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## Legislative Assembly of Ontario

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## Official Report of Debates (Hansard)

Thursday 13 February 1992

### Standing committee on administration of justice

Advocacy Act, 1991,  
and companion legislation

## Assemblée législative de l'Ontario

Première intersession, 35<sup>e</sup> législature

## Journal des débats (Hansard)

Le jeudi 13 février 1992

### Comité permanent de l'administration de la justice

Loi de 1991 sur l'intervention  
et les projets de loi  
qui l'accompagnent



Chair: Mike Cooper  
Clerk: Lisa Freedman

Président : Mike Cooper  
Greffière : Lisa Freedman

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# LEGISLATIVE ASSEMBLY OF ONTARIO

## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

Thursday 13 February 1992

The committee met at 0944 in committee room 1.

### ADVOCACY ACT, 1991, AND COMPANION LEGISLATION LOI DE 1991 SUR L'INTERVENTION ET LES PROJETS DE LOI QUI L'ACCOMPAGNENT

Resuming consideration of Bill 7, An Act to amend the Powers of Attorney Act; Bill 8, An Act respecting Natural Death; Bill 74, An Act respecting the Provision of Advocacy Services to Vulnerable Persons / Projet de loi 74, Loi concernant la prestation de services d'intervenants en faveur des personnes vulnérables; Bill 108, An Act to provide for the making of Decisions on behalf of Adults concerning the Management of their Property and concerning their Personal Care / Projet de loi 108, Loi prévoyant la prise de décisions au nom d'adultes en ce qui concerne la gestion de leurs biens et le soin de leur personne; Bill 109, An Act respecting Consent to Treatment / Projet de loi 109, Loi concernant le consentement au traitement; and Bill 110, An Act to amend certain Statutes of Ontario consequent upon the enactment of the Consent to Treatment Act, 1991 and the Substitute Decisions Act, 1991 / Projet de loi 110, Loi modifiant certaines lois de l'Ontario par suite de l'adoption de la Loi de 1991 sur le consentement au traitement et de la Loi de 1991 sur la prise de décisions au nom d'autrui.

### REGIONAL GERIATRIC PROGRAM OF METROPOLITAN TORONTO

**The Chair:** I call this meeting of the standing committee on administration of justice to order. I would like to call forward the first presenter from the Regional Geriatric Program of Metropolitan Toronto. Good morning. Would you please identify yourself for the record and then proceed.

**Dr Gordon:** I am Dr Michael Gordon and I am a geriatric specialist. I am here on behalf of the Regional Geriatric Program of Metropolitan Toronto. I would like to thank the committee for giving me the opportunity to present. I have a special thanks because of the advocacy position of the committee. Last night when my furnace broke down at 8 o'clock and they told me it would take eight hours to get it repaired, I said, "Please help me; I have to be at the Legislature in the morning," and it only took six and a half hours and I did not come as an iceman. I just wanted to let you know that there has been progress.

I am here presenting because I and many of my colleagues on the regional geriatric program that consists of geriatricians, psychogeriatricians, that is, geriatric psychiatrists, primary care physicians and a whole range of health care providers have concerns about the legislation as written. You have a copy of a document, which I will not read because it would take too long. It is here for your reference.

We feel of course that it is laudable to protect people who are vulnerable and it is important society takes a role in making sure people's needs are met. But we are very concerned that while doing this we should not undermine the basic premises on which care is based. With the increasing number of elderly people in the population and the increase concomitantly of those with cognitive impairment due to a wide range of illnesses such as Alzheimer's disease, multi-infarct dementia, that is, multiple strokes, Parkinson's disease, we will be facing over the next two decades an inordinate number of people whose mental function is compromised because their brains are afflicted with diseases for which we have no effective treatments at this point.

We know at present, and this will continue into the future, the primary care responsibility of this group of people is left to informal care givers, that is, devoted and committed family members. It is on the basis of this family network and fabric that society can be assured that people with these problems will be looked after. Certainly in Canada and most of the western countries in which there are data it is clear it is the primary family care givers that supply the predominant amount of care.

The feeling of many of us who have looked at this legislation is that, although perhaps not intended to do so, it seems to assume the worst of care givers and caretakers, that is, they cannot be trusted to carry out their mandate that is part of their family responsibility or their mandate that is part of their professional responsibility. The feeling is if that is the assumption on which we have to work, then as a society we have very severe problems because we will never be able to legislate how people feel about each other, care about each and how families are devoted to each other.

One would have to imagine some kind of external force interposing itself in all kinds of family matters and dynamics if we could not believe that family members essentially cared for each other. For anybody who has been responsible for someone he loves who has been dwindling and failing because of cognitive impairment, one is aware of the enormous sacrifices and sometimes burdens of responsibility that are taken with great commitment by these families.

We feel the legislation as written creates a bureaucratic nightmare—that is the best word I can use—which although it may help a few marginal people who do not have networks and who do not have ways of getting people to speak on their behalf, the price that will be paid is the undermining of the wellbeing of the great majority who do have a network of informal and devoted care givers.

Of the three major acts, Bills 74, 108 and 109, our major concern is with the Advocacy Act. We feel this creates an unnecessary layer in achieving the goals of caring for

people, that the advocates—without going into the details while speaking; it is in the written material—have extraordinary powers. I said humorously at a meeting, but as I look at it I am not sure I was all that off, that they have powers I do not believe even the RCMP have in terms of their ability to enter on the basis of suspecting there might be a vulnerable person. I know English is a peculiar language. The word “might” has many meanings, but “might be vulnerable” sure opens the door to many situations. I think that to give such powers to any group of people should be a concern.

0950

Another concern in the legislation, as I and people we have spoken to understand it, is it seems the liability and accountability of the advocates are very modest compared to their potential impact. Most of us who are professionally based care givers have an accountability that is professionally based, a liability that is both professionally and legislatively based, and they are much more circumscribed than seems to be the case for a group of people who with whatever the training could be imagined for them might have enormous impact. We feel even if there were an Advocacy Commission and advocacy legislation, that amount of limited liability and accountability would not give sufficient direction and counterbalance to the activities of the advocates as they are described.

One of the major concerns is that the advocacy legislation and how it interfaces, for example, with the consent to treatment would interfere with the basic, ordinary clinical care that all of us in the geriatric field are involved with. It would not only obstruct ordinary decisions on which the care of this group of people depend, but also potentially disrupt the fabric of relationship and trust between family members, health care professionals and their clients/patients. At times it might be impossible to assess a person's meaning of words by somebody who is not really trained in the field and could take things at face value; in other words, words as they are said as opposed to what they might mean.

I want to give a little anecdote because since I read this legislation I have been looking very carefully at my particular practice, which is exclusively a geriatric practice, to see what the potential involvement might be. Last week I saw a family. The son immigrated a year and half ago, leaving his two parents who were European-born to join him after he got settled. After he left, he heard from his mother that his father was quite despondent about what was happening. Everybody attributed it to his leaving, so plans were hastened for them to come. It took about six months. He got established. The family came, that is, the mother and father. That is the only family they have; the rest were destroyed during the Second World War.

They came, and with the adjustment of coming, the family, that is, the wife and the son, did not really pay attention to the details of what was happening to the father who was beginning to fail. After a while they realized these were not just adjustment problems so they went to their family doctor and explained what was going on. The family doctor felt that something unusual was going on and referred him to me.

I saw him. It took between 20 minutes and a half-hour for this gentleman to relax sufficiently to actually converse with me. It is hard because I cannot stand up, but towards the end of the 20 minutes he started holding my hand. That was a sign of trust. I spoke to him in a combination of four languages, none of which I speak very well, but none of which he spoke very well either because they were all the most recent languages he learned. He spoke many languages. I was not sure if his mother tongue was Russian or Hungarian, neither of which I speak. The history was taken in four languages, with the son interposing Hungarian. At the point I realized that clearly this man was suffering from cognitive impairment, it was 4:30 in the afternoon. They had travelled a good distance to get to me. I wanted to do some blood tests and perhaps stop a medication he had been put on.

According to the legislation as I understand it, I would not be able to do that. I would have to first inform him in writing—I am not sure what writing I would even inform him in—of what my assessment was. Then presumably on a cellular phone or something I would call somebody who either was sitting in my office, which would be unlikely, or riding around on a motorcycle and could come hopefully immediately to help me with this. That person would presumably inform him—in which language again I am not sure—what his position and rights were.

Meanwhile the wife was crying as she realized how poorly he was doing in his mental status and how impaired he was, because they had never done it formally. They knew there was something wrong, but they had not watched the process of formal assessment of cognitive function. That whole process I would have had to stop for no reason, because I do not believe anybody could have communicated to him or got much more information than me or another physician who is knowledgeable in the area, and that a simple continuation of his care would not have been possible without invoking this network of activity. Even something as simple as saying, “Stop taking the medication you're on,” officially I could not tell him that. I could not tell his wife because of course he never designated her as a formal substitute decision-maker. Why would he have? They have been married for 50 years. I presume he assumed that she would be, or the son.

That was an example, and I have had multiple similar examples that I think would reflect the impediment that ordinary care would suffer by this legislation.

I think we can achieve, and I think the group I represent can achieve, many of the goals of vulnerable people by building on the structure that already exists, without creating a new superstructure. Part of the basic structure is the informal structure, which is the family and the care providers and the care givers that already have accountability, professionally and legislatively. On that we can build in, based on structures that already exists within the institutional sector, within the community sector, ways of making sure that those who may not have family advocates or may have families that are not as attentive as they might be can be adequately looked after, and that their rights and autonomy, when this is what the issue is, are respected.

In the handout I gave you there is a quote, which I would like to read, from a professor of philosophy from the United States, which was quoted in the Gerontologist. It says:

"Although it must be acknowledged that some families abuse or otherwise fail to service their elderly members, it will not do to use that as an excuse to ignore preferences and to undermine the privacy and empowerment of families to serve their own by good faith and surrogate decision-making.... we need more research not only on family abuse of the elderly, and more research and data not only on how and when family involvement in surrogate decision-making goes awry, but also research on how well family surrogate decision-making works without formalization and appeal to the judiciary and.... under what circumstances surrogate decision-making is accomplished within the social nexus of families so that we are no longer surprised or suspicious when an informal system of tradition and custom works well."

We have made a number of formal recommendations to the committee that we feel will fulfil the goals. They are written. I will just quickly go over them.

We feel the proposed advocacy legislation should be cancelled. We do not think it can be tinkered with and made to work better. We think it is basically flawed. It is cumbersome, expensive and creates another level of bureaucracy that is not required to fulfil the needs of vulnerable people, especially those with cognitive impairment.

We think there are alternatives, such as strengthening and increasing the mandate of the office of the official guardian or legal aid system or some combination thereof. Consider giving them an advocacy role so that patients and families in need or health care professionals with questions or problems can turn to them for advice and assistance in some kind of structured manner, not in this urgent suddenly-stopping-what-you-are-doing manner, because this is a long process. Cognitive decline may take many years.

Reconsider the implications and judgement of giving powers to advocates who clearly will not have the training, background or professional framework to merit such an extreme degree of power. I will not finish reading that one; it is a long one.

1000

Codify—this seems to be in the acts but not as clearly as I think it could be—the chain of substitute decision-makers as exists within the hospital setting and let everyone know in the province that this is the law, that unless they do otherwise they will have, if they are no longer competent, a decision-maker made on their behalf following a structure. If they are not happy with it they can, in advance, do a directive health care proxy, as exists in New York state now—I have just done it with my family in New York; it took them five minutes—to designate somebody instead of the person in that chain.

Simplify the substitute decision-making process. Simplify the consent to treatment and acknowledge that there is a range of decisions where consent is implied, from routine to invasive clinical activities, that do not have to be dealt with in same way. In this act the standard for consent is very high and one must question the reasonableness and

necessity to create a standard of consent, usually assigned to invasive and clearly risky related interventions, for routine clinical activities, which in general take place in most circumstances by assent and for which there are potentially major benefits and very marginal risks, such as blood tests, stopping medications, introducing medications, non-invasive imaging etc.

Give the health care practitioner the responsibility of formally informing, with appropriate documentation and a system of professional audits, patients of their right and opportunity to see and have advice from some system of advocacy such as we suggested before, through the public guardian, through legal aid—some system without creating a new one.

Enhance long-term care facility advocacy by mandating this function to family and/or patient advisory committees where they have a clear role in dealing with concerns and have an external responsibility and accountability so that they will not be in a conflict of interest.

Strengthen and enhance the presently existing coroner's geriatric and long-term care committee so that it can be not only reactive but proactive in defining standards of care and needs to assure that people who are in need are cared for properly.

Most important, support the role of families, other care givers and health care professionals through education and access to assistance so that they can fulfil their crucial role as the fabric and foundation on which all care depends. Major portions of these acts in many ways conflict with the philosophy and expectations expressed in the present government's redirection of long-term care, which depends so heavily on the support and commitment of the very same family care givers who we seem to imply should not have that degree of responsibility. Thank you very much.

**The Chair:** Thank you. Each caucus will have about four minutes for questions or comments.

**Mr Sterling:** I do not disagree with what you are saying. I think the advocacy system under Bill 74 is a real problem. It is going to be an expensive endeavour not only for setting up the commission and providing the advocates but for you as a physician to treat a patient because there are going to be delays, there is going to be extra paperwork, there are going to be a lot of different administrative hangups occur because of advocates, which is not going to lead, in my view, to a care system much better than it is at this time.

The problem, I guess, that we face politically is that there are many groups out there that insist that there be an intrusion. There is a mistrust of the health care provider and somehow they have won the day in terms of bringing this legislation forward. How do we placate them in dealing with advocacy services to some of the people who have been taken advantage of in the health care system? You mention the legal aid system; you mention the guardian's office. I think we heard earlier this week that the guardian was estimating that under this system it was going to cost something like \$42 million more for his office under the present situation. How do you trigger the mechanism for an

advocate to come into a situation where there is not a supportive family?

**Dr Gordon:** Clearly there are groups of people in all walks of life who do not have the kinds of supports one would expect, be they children or be they people with a cognitive dysfunction or physical disabilities. We can introduce, as I mentioned, in the formal care-giving system such as nursing homes etc, a system where advocacy is built in with an external accountability.

This happens now, I can assure you. I work in a large centre where the social workers have very strong feelings about their role as advocates. One could say, "Yes, but they work inside a facility so they have a conflict of interest," but if one introduces an external accountability they are responsible for, it allows them to have that role without feeling they are jeopardized in terms of their work inside. You do not have to create a great deal to do that. These people are already working there. You just have to make sure their mandate is understood.

I think it is a real shame that there is a mistrust of the health care providers of this province. I know doctors get it, fine, but we are talking about social workers, nurses, occupational therapists and physiotherapists. Most of us in health care have gone in there because we are intrinsically advocates; that is why we do it. Of interest is that this law for people like myself is a bonanza. For general psychiatrists, this is a bonanza. We are going to be getting consulted five times as often as we are now to ensure that somebody has been second-opinioned. I could probably retire next year.

But to me that is not a good way to use a system. We want to make sure that those who are at risk can be identified. We have an accountability to identify people we suspect are at risk. Right now, for example, if I see somebody who I believe cannot drive because of an illness, I am responsible for reporting him or her to the motor vehicles office. I am liable. Once people are liable to do that, they have an accountability. You can build that into systems that already exist for those people who are marginal or who are vulnerable.

I think for some of the unregulated facilities one might have to look at how you would regulate them in a way that does not overtake or necessarily impose a great deal of financial cost and make sure there are standards and expectations of the rooming houses, of the retirement homes—the places that right now are not regulated—so they too have an accountability. I think that can be accomplished, thereby meeting the needs of many of the people who are believed to be at risk without creating a whole new super-structure that will in fact interfere with the everyday care of the vast majority of people.

**Mr Poirier:** I am looking at your third recommendation. Obviously you are quite correct that the vast majority of the people may be well cared for and whatever, but what about those where there is a definite case of abuse who do not have any family whatsoever? When you say, "Therefore, eliminate the ability of so-called advocates under any system or structure to enter homes/institutions, or have access to records in any way that threatens privacy,

security, confidentiality," in principle, if I am the devil's advocate, do you not think that maybe goes a bit far for certain cases where there is abuse of somebody who has absolutely no family whatsoever?

**Dr Gordon:** Yes.

**Mr Poirier:** Should not somebody somewhere have this power to do so?

**Dr Gordon:** Yes, and it should be given to them with due process; in other words, if somebody suspects that there is something going on, as we do in the police system. The police cannot just walk in even when they know something is going on; they have to get a warrant. There are things they have to do. We should be able to facilitate when there are reasonable grounds. I am not talking about extreme grounds but reasonable grounds where somebody has said, "Boy, there's something funny going on there."

I grew up in New York. We had apartment houses and the reason you knew somebody died was the smell. That is a tragedy. That should not happen. Autonomy allows you to have the right to rot, and that is an extreme. With reasonable suspicion there has to be a mechanism by which people will—whether it is through a warrant; that is in the act in one form—be able to go in. If records have to be obtained, there is a mechanism for that. We have it in the Coroners Act now. There is a system to do that. You do not have to create a new system, I believe, in order to accomplish that. I am not denying there are people at risk, as there are children, and we have ways of dealing with it. We must deal with it. You do not want to leave people who are not being cared for vulnerable.

1010

**Mr Poirier:** I agree with you, but then why do you say "under any system or structure"? From what you are explaining, it does not jibe with what you—

**Dr Gordon:** Well, that threatens privacy, security, confidentiality. When I say "threatens," there has to be a process with, I would say, a warrant. The way it is written, and maybe I am reading it wrong, if I as an advocate suspect someone might be at risk, I can go in. Now that is pretty presumptive in terms of rights. If I or whatever the advocate is believes there is something there, I should be able to present my case to whoever it is that I believe and then get a warrant.

Records mean the subpoenaing or the warrant to get records. There is something in the act that says you can remove records under certain circumstances from an institution. We never let records out. A photocopy is one thing, but removing the original record? We never do that, because once you have done that you do not know what is done to the record. We just never allow it, yet this act says you could do it. When I say that threatens privacy, people should know that you cannot just walk in unless there is some due process. Security is the same thing, and confidentiality. Until there is a due process one should not be allowed to enter because there is a belief that something might be wrong. That is an enormous degree of power.

**Mr Poirier:** Obviously the manager of the institution under whatever system sees somebody, whoever that may be, come in and grab the dossiers and the seal and take

them away as the police will do sometimes. Obviously the manager of that institution will feel that it is an invasion of privacy and confidentiality or whatever. But then, too bad, right?

**Dr Gordon:** No, no. If the process is there, and the coroner's office has it now, that you believe something has gone on, there is a process that says you can do it. Whether your manager likes it or not, you do it. I have been on the receiving end of that. I have wrapped up many files to go to coroners' reviews, because that is part of being in long-term care. If somebody says, "I'm not happy," then the files go. That is due process. Somebody has to have permission to ask for it. Somebody has to say, "Something's gone on there." I have no problem with that. I have a problem with somebody, based on an individual's suspicion, having enormous powers.

**Ms Carter:** I am really quite distressed that you are targeting Bill 74, the Advocacy Act, in particular because I really do not see your grounds for doing that in spite of all you have said.

First of all, as we all know, there are people who do fall through the cracks, who do not have family, friends, networks of support and so on. Let's face it, just now and again the family or the facility where the person is may be mistreating them. You compared the advocate to the RCMP, but the situation is that advocates can go to where the person is because they need to get together with him, and this is the only way they can do it. They cannot force entry. If entry is refused, they do have to go and get a warrant. The only power that advocate has is to listen to the person, to hear his views, and to try to follow those up to carry out the wishes of that person.

I really do not see the threat that you are suggesting in this context. In fact, I would say that if you do not have a system of this kind there is going to be an ongoing body of people who are going to fall through the cracks and who are not going to be heard from and listened to.

At the moment, as you know, we do have an advocacy system in the psychiatric hospitals. I understand that this works quite well, but on the other hand there is a problem because they do in a sense lack independence. They are responsible to the Ministry of Health. I feel that, far from setting up an extra bureaucracy, as you said, we are creating a body of people who will be at arm's length from any ministry. The commission will be independent, although I know it is being set up initially by the Ministry of Citizenship, and this will give those people much greater freedom to advocate for that disadvantaged person.

As regards records, I understand that they would only be able to look at records of a person with the consent of that person. So I do not see the threat there.

As I say, I am mystified as to—

**Dr Gordon:** Let me read it, because maybe I am misreading. It says, "An advocate is entitled to enter a facility where there are or may be vulnerable persons, without a warrant and at any time that is reasonable in the circumstances." Subsection 21(1) says, "An advocate is entitled to enter, without a warrant and between 8 am and 8 pm, premises where he or she has reasonable grounds to be-

lieve that there is a vulnerable person who wants or could benefit from the services of an advocate."

To me that gives a lot of freedom to advocates to enter, if they believe. The concern I have when you say, "If the person gives permission," is that a good part of my practice is dealing with people with cognitive impairment. Getting a person with cognitive impairment to agree to something is not hard. They can agree to all kinds of things; they can say all kinds of things. If we are basing an action on somebody's request—they may request to go back and start their business.

I look at the training. Many of us take many years to have the sophistication of understanding how to tease out what is meaningful, what is delusional, what is hallucinatory, what is not sound in terms of people with cognitive impairment. I had a patient recently whom I had to report to the Ministry of Transportation: "I want my car back. Why have you done it? First of all my wife took the keys away from me." If anybody walked in and listened, he was very eloquent. He said, "Look, I walked in here. You took my keys away. I've been driving for 25 years. I've never had an accident, da-da, da-da." How does somebody know that what that person says is valid? I know it is not valid. I have assessed him over a period of—

**Ms Carter:** We are not asking the advocate to make a judgement, but I think it is reasonable that patients, whether they are delusional or otherwise, can have as you might say an independent line to the wider community, other than the people who are already there, if they so wish. Maybe it would be justified, maybe it would be in some cases delusional and that would be followed up.

**Dr Gordon:** If you took it at face value you would say, "We will have to have another assessment for this person." From my point of view, I am going to retire probably a wealthy person, because there will be lots of people who will say things that people can take at face value, and then you will say, "We will get another opinion and another opinion." Who will be the final opinion-maker, since clinical opinions are opinions based on various degrees of expertise and we often disagree with other people's opinions? What will be the final gold standard of opinion? I do not know.

I believe that, as written, this gives enormous powers that are far beyond the powers necessary to deal with the people who clearly fall through the cracks. I do not believe you make legislation to deal with people who fall between the cracks that impacts negatively on the vast majority of people who do not fall through the cracks.

**The Chair:** Thank you, Ms Carter. Mr Malkowski would like one quick comment.

**Mr Malkowski:** I would like to respond to some of the comments you made. You have said that there are a few marginal people out there who may require advocacy, but just to be very upfront, coroners' reports and the O'Sullivan report have both come out very strongly that the advocacy system is essential. We have heard from advocates groups as well as consumer groups that have come out very strongly in support of the need for advocacy. Are you saying that vulnerable people who have been

exploited, who have suffered neglect and abuse, are not entitled to a broad advocacy system, and it is something you do not need? Would you not agree that there are people who are in need of advocacy?

**Dr Gordon:** Is this to me? I agree completely, and I said there has to be a system, but the system does not have to be created that negatively impacts on the large group of people who have a system of devoted care givers. You create a system for those who do fall through the cracks, who do not have a structure to support them, that you make sure is there and is utilized. There are ways of doing it without creating a new infrastructure.

**Mr Sterling:** I asked on Monday if the Ministry of Health had any kind of statistical information regarding the need for advocacy of vulnerable people. I have not received a response whether there is any statistical information.

**The Chair:** I have just been advised that it will be forthcoming.

**Mr Sterling:** Okay, fine.

**The Chair:** Dr Gordon, on behalf of the committee I would like to thank you and your colleague for taking time out of your busy schedule to come in this morning and give your presentation.

**Dr Gordon:** Thank you very much.

**Mr Sterling:** Mr Chairman, at this juncture I would like to submit to the committee notice of three motions to amend Bill 109. The government seems reticent about taking any leadership with regard to suggesting amendments to this bill, and I think it would be much easier for proponents who come before this committee to have suggestions for amendments so that they can talk to real suggestions as to how these bills can be made better. I would ask that these be delivered to the various members of the committee, and I would also ask that each proponent who comes before the committee be supplied with a copy of these and that future proponents be supplied with a copy also.

**Mr Morrow:** On a point of order, Mr Chairman: Maybe I am not understanding the situation right, but would that not be done during clause-by-clause?

**The Chair:** The amendments can be submitted at any time.

**Mr J. Wilson:** The sooner the better. We will not have to debate the points over and over.

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#### ONTARIO HOSPITAL ASSOCIATION

**The Chair:** I would like now to call forward the next presenters from the Ontario Hospital Association. Good morning. Could you please identify yourself for the record and then proceed?

**Dr Dare:** I am Wilma Dare, current chairman of the board of the Ontario Hospital Association. I thank you for the privilege of presenting the views of the association on these three important pieces of legislation. I would also introduce our senior counsel, staff of the OHA, Carolyn

Shushelski. I am conscious of time limitations and I will try to adhere to same.

Quite simply, the Ontario Hospital Association believes that as a package, these bills are unworkable. In principle, we are not opposed to the creation of a system of patients advocates, we are not opposed to the guardianship mechanisms proposed in Bill 108 and we are certainly not opposed to strong consent to treatment legislation. We are in fact on record as being fully supportive of these goals. What we are opposed to is legislation whose main effect will be to plant a barrier of bureaucracy between our patients and the care and comfort to which they are entitled. That is our primary objection, but I must also point out that in this age of ever-tightening health budgets, implementation will result in expanded hospital costs.

I will discuss each bill in turn. The intent of Bill 74 is to give a voice and powers to individuals who have often been ignored, and no one can quarrel with that. But like its two companion bills, it is a prime case of overkill. All of Bill 74, the Advocacy Act, seems to be driven by an assumption that hospitals are careless or casual about the vulnerable person who may be under their care. This is definitely not true.

Think about it. The Advocacy Commission and the corps of advocates envisioned in this legislation are to be given an extraordinary range of powers. The act does not even specify who is to deem a person to be vulnerable. Is it to be the advocate? You can look from one end of the bill to the other without finding any mechanism by which complaints about the advocate's actions and decisions may be registered.

An advocate will be entitled to walk into a hospital where there are or may be vulnerable persons. The advocate will be able to enter the facility without a warrant and at any time that is reasonable in the circumstances. There is no provision in the act to explain what is reasonable, nor in whose opinion it is reasonable. Further, it is an offence to hinder or obstruct an advocate.

Such wide powers raise very serious concerns. As the act now stands, an advocate can simply walk into a facility and seek out vulnerable persons. Given the broad definition of "vulnerable person," almost any person in a hospital setting could be considered to be so. Confrontation between health practitioners or other hospital staff, such as security personnel, and advocates as to what is reasonable in the circumstances must be avoided. It is in the interest of all parties that a cooperative atmosphere be maintained under these circumstances. Quite clearly, some reasonable and probable ground rules should govern an advocate's right of entry to a facility such as a hospital. Also, the head of a hospital should be given notice of an advocate's intention to visit a vulnerable person.

Apart from the extraordinarily wide powers implicit in individual advocates' access to facilities and records, the commission's mandate is to effect structural changes at the legal, social, economic and institutional level. To this end, it is proposed that the commission be given broad regulation-making powers.

Again, one can appreciate the intent behind the legislation, but please look at what this proposed legislation actually

is: It is an act that gives very wide powers to one group, and that is a dangerous thing to do, no matter who is involved, without some system of checks and balances.

I urge you to read our brief on Bill 74.

The Substitute Decisions Act, Bill 108, provides for powers of attorney and other guardianship mechanisms that may be obtained by or on behalf of incapable or potentially incapable people.

What I wish to bring to your attention this morning, however, are the serious concerns that emerge when this bill is seen in the light of proposed Bill 109, the Consent to Treatment Act. As it is now written, Bill 109 places an unfair and unreasonable onus on health practitioners to determine whether any of these guardianship and power of attorney measures obtain in the case of their patients. Even in non-emergencies the time required to determine whether a guardian or attorney under a power of attorney for personal care must be consulted and, if so, who this person is and where he or she might be found could result in delay of treatment causing needless distress and suffering.

In short, the legislation is impractical and unmanageable in a hospital treatment setting. Faced with this quandary, the only mechanism we can conceive is the establishment of a registry system. Such a registry would have comprehensive information concerning the holders of powers of attorney and other guardianship instruments. Realizing this would entail a great deal of expense and resources, I ask if this is feasible.

In emergencies, it could be a matter of life or death. Section 23 of Bill 109 stipulates that a practitioner may not administer emergency treatment if he or she has, first, reasonable grounds to believe a patient has a power of attorney for personal care containing instructions to refuse consent to treatment of the kind proposed, and second, no reasonable grounds to believe that the patient has subsequently expressed wishes that would override the instructions.

This section also provides that emergency treatment cannot be given if the practitioner has, first, reasonable grounds to believe that the person, when capable, expressed a wish to refuse consent to such treatment, and second, no reasonable grounds to believe that the person expressed other wishes that would override the original wish.

What is a practitioner to do in the by no means unlikely situation where he or she has to decide within minutes whether to save someone's life with, say, intubation to restore an airway or another medical procedure? It is unreasonable even to ask practitioners in such circumstances to hunt around for legal documents like powers of attorney. But Bill 109 is also requiring them to decide what a patient may or may not have wished. What are reasonable grounds in such circumstances? What if there are two relatives present, one saying the patient wishes one thing and the other saying the patient wishes the opposite?

We also recommend that the government conduct a public awareness campaign to alert people to the provisions of Bill 108 and its intentions and the advisability of obtaining powers of attorney and/or other instruments well in advance of a crisis.

Now to turn to Bill 109. As with Bill 74, our quarrel is not with the intent of the legislation. Rather our complaint

is that the Consent to Treatment Act is unworkable legislation. There is a very real possibility that patients, particularly the elderly and frail, will end up having their civil rights protected to the hilt while they are denied the immediate care and comfort to which they also have a right.

Consider the case of a senior suffering from senility, who has injured her wrist in a fall. She is brought to a hospital. Her injury is not an emergency as defined by Bill 109. Even so, she is in pain and in need of treatment. She is also conscious and obviously incapable. Therefore, the physician must advise her of her rights under section 10 of the bill.

This would mean that the health practitioner must advise the patient of the finding of her incapacity to consent to the particular treatment and must give the patient written notice that he or she is entitled to meet with an advocate and make an application to the Consent and Capacity Review Board. The health practitioner must notify an advocate. The advocate must meet with the patient and explain the effect of the finding of incapacity and the patient's right to make an application to the board. The advocate's explanation is sufficient even if the patient does not understand it. If the patient chooses to exercise these rights, the health practitioner cannot administer the treatment until the board makes its decision and any appeals have been disposed of.

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This woman needs her wrist fixed. To be sure, her rights must also be protected, but must she suffer pain and other distress while that is happening? If Bill 109 is passed unamended, that will be the fate of many men and women like her.

This is no rhetorical exaggeration, and to further illustrate what I mean here I refer you and your committee to appendix A of our brief. It contains a number of scenarios describing situations that could very realistically arise if Bill 109 is passed in its present form. The scenarios are the work of an OHA task force of physicians, nurses and hospital administrators who were asked to consider the legislation in light of their everyday, practical experience.

Besides the woman with the injured wrist, you will find the example of the young child who refuses to be given a needle. Under Bill 109, he is demonstrating a wish to refuse consent on his behalf. By definition, he is incapable with respect to the treatment. Thus, the physician must advise the child of the finding, give him written notice that he is entitled to meet with an advocate and make an application to the Consent and Capacity Review Board.

An advocate must also be notified of the finding and meet with the child to explain the effect of the finding and his right to a board hearing. If the child wishes a hearing, treatment cannot be given until the board gives a decision and any appeals have been disposed of, or the period of appeal has elapsed.

Much of this bill seems to us to have been written with major decision crises in mind: such situations as parents' disagreement with courses of treatment that their children sincerely desire, cases where the terminally ill do not wish to have their lives artificially prolonged, cases in which patients have ethical or religious objections to certain

courses of treatment and situations where the appropriateness of institutionalizing a person is in doubt.

No one can quarrel with the need for the law in these areas to be spelled out more clearly. However, Bill 109 is written so that it not only covers these areas but also spills over into routine hospital operations with the result that patients may not receive and practitioners may not deliver the immediate care and comfort that is needed.

In the scenarios attached to our brief you will find a number of other ways in which Bill 109 could very well result in patients not receiving treatment that is necessary. In one of these cases you will see how hospital staff may be restricted from protecting disoriented people from wandering away from a hospital into potentially dangerous situations. Surely that is not the intended effect of this legislation. We certainly do not think it is.

Accordingly, the focus of our recommendations is the achievement of legislation that simultaneously protects patients' rights and does not deny them the immediate care and comfort to which they also have a right. Achieving this is a matter of addressing the fact that the most serious practical flaw of Bill 109 is that it ignores the wide grey area between situations that are, without doubt, emergencies and those that are quite clearly not emergencies.

Part of the remedy is the revision of the definitions of "emergency" and "treatment" and other sections of the bill so that health practitioners will not be prevented from administering basic assessments, care and treatment to patients like the woman with the injured wrist. Of course her rights must be protected, but is there anything fundamentally wrong with a physician providing basic treatment for her wrist and relief for her pain and distress while informing the advocate at once that the patient is incapable and treatment has begun?

This would serve three ends: The immediate care and comfort to which the patient is entitled would be provided, the chance of her condition worsening would be greatly reduced and the advocate could be on the scene early enough to make a timely consideration of the patient's overall treatment in terms of her rights and wishes.

This is not an abstract situation. Some hospital emergency departments see as many as 200 patients a day. Many are elderly and confused. Others may be intoxicated or under the influence of drugs. Most need treatment, and putting the full weight of the patients' rights machinery between them and what is largely routine treatment will serve no one at all.

I pose a question to you and the members of your committee. Is there really such suspicion and distrust of hospital and health practitioners as is implicit in this legislation? I am not saying that things do not go wrong and that patients do not need strong mechanisms to protect their rights and pursue their grievances. Speaking as this year's chair of OHA and as a physician, I am rather saddened and, to a degree, resentful of any assumption that the thousands of men and women, professionals, who work in our health care system have no concern for their patients and their patients' rights.

Quite recently, a member of my staff was talking to a person interested in this legislation and that person ex-

pressed surprise that health professionals and hospitals were so upset about Bill 109. "What are they worried about?" this person asked. "Bill 109 has made a provision that if health practitioners follow the rules, they won't be held liable if they do not treat the patient." This, to us, is a chilling example of the negative atmosphere that is clouding this legislation, the assumption that patients need to be protected from those who work in our hospitals.

Further, we have concern that the protection from liability provisions are not consistent or adequate. For example, failure to provide necessities of life is an offence under the Criminal Code of Canada, but it is not clear whether health practitioners are protected from such criminal liability by acting according to the rules of this bill.

We are appearing before you to protest the legal barriers that would prevent health practitioners from providing proper treatment promptly. Therefore, although OHA appreciates the well-meaning intent of this legislation and strongly agrees that patients deserve the fullest protection of the law, we must conclude that these bills do little to further those goals.

We urge most sincerely that this committee take the option of recommending the withdrawal of Bill 109 as constructed so that we may start afresh. As it stands now, this legislation will serve only to make our health care facilities places where caring and treatment of patients is secondary to bureaucratic and legal niceties. With few exceptions, patient care is not a matter for the courts. Only by doing that will we begin to create laws that are truly in keeping with our patients' rights, wishes and individual interests.

I thank you for your attention, and I would be glad to attempt to answer any questions your committee members may have.

**The Chair:** Thank you. Each caucus will have about three minutes. Mr Curling.

**Mr Curling:** Thank you, Dr Dare, for coming in. I know it is no surprise if we tell you that many of the things you have said now have been said by others here.

I am very happy to know that you have also seen the necessity of having these bills and these laws put in place, the Advocacy Act and the Substitute Decisions Act and the Consent to Treatment Act. You said they are necessary, but you emphasize right through, like many who have come here before, that the way it has been done is very adversarial. It needs proper definition. It creates barriers, because of the bureaucracy in which they have been created, all through the three bills themselves, especially setting up the commission.

Do you feel that the bills are a bit too hurried and have not been thought through? Why I say that to you is that during the presentations, many of us on this side—not on the government side—had to ask for clarification from the counsel and the parliamentary assistant many times. Do you think it is a bit hurried and that is why it is like that? I think the government has good intentions. Just as you say, these acts are well-intentioned but are extremely flawed. Do you see it that way?

**Dr Dare:** I am in no position to say whether it was hurried or not, because I do not know how much time and effort was expended. I do say that those who have been involved in drafting these bills have not had the practical experience of the treatment setting in a hospital, with which we are most concerned. I think it would be outside my privilege to say that they were hurried, but I do say they are flawed, because they are not taking into consideration the practical application of the provisions of these pieces of legislation.

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**Mr Curling:** In the short time we have, I wish to ask you some questions. There is a part in here where you said the Consent to Treatment Act is unworkable legislation. Now every piece of legislation is about people and how they interact in society, and there is a process in which they should behave. Many of your colleagues from the medical practitioners' area stated that as they walk through the legislation, they find an insurmountable bureaucracy, that they could not get through the heap of paperwork and decisions to be made.

If it is unworkable, do you get the impression then that they have not walked through this process, to say, "Here is a patient" and "Here is someone"? In the emergency department, as you said, 200 would come through some days for whom you would have to get permission and find out if it is okay to proceed. Does the doctor have the necessary authorization? Do you see chaos in the emergency areas because of this legislation? I am using the word "chaos" without any qualification; I just say "chaos."

**Mr Poirier:** Ordinary chaos.

**Dr Dare:** Ordinary chaos. Above and beyond what often exists in the exigencies of a large patient load in an emergency department, it does, in my view, impose requirements on the health practitioners in that setting which are adding to the burden of their decisions and the urgency of their care when it is unnecessary to protect the rights of the patient. A simpler procedure and the relief from some of the intricate bureaucratic provisions of this bill would still accomplish the purpose without this overkill in terms of procedures and legal niceties, as we say in our brief.

**The Vice-Chair:** Mr Poirier, did you want to comment?

**Mr Poirier:** Yes. Do I have some more time? That is good.

**The Vice-Chair:** If you make it brief, please.

**Mr Poirier:** As usual. We are quite cognizant of the nature of your worries with the bill. You are definitely not the first one from the medical profession to come forward with this. We are very sympathetic to you and we think you are quite correct in the difference between the theoretical application of the bill and the practical aspect of what happens in reality in the emergency situation. Thank you again for bringing that forward.

**Mr J. Wilson:** As has been said, a number of your concerns have been brought to our attention, not just in the three days of hearings we have had, but of course your staff have done an excellent job of meeting with each and

every one of us and ensuring that we are aware of many of the problems in the bill.

Because you have so many recommendations in your brief, it is difficult to pick out one, so I am just going to ask you a question, because I think you are dead-on and show a lot of courage when, near the end of your brief, you asked the question, is there really a great deal of suspicion out there about the service provided by our hospitals and our health care practitioners? I am worried too about the underlying philosophy or the philosophical underpinnings of this legislation. Is it having a direct effect on morale now in the hospitals and among your association, or will it, if enacted as is?

**Dr Dare:** I do not say it is having a direct effect on morale now. It is only one evidence of a climate that surrounds us at the present time. Certainly I can speak for the hospitals, as chairman of their association, and also for health care practitioners, that they have enough confidence in their aims and objectives not to have their morale affected by any such evidence or assumptions.

**Mr J. Wilson:** That is good to hear, for the sake of the system. One of the recommendations I am very much interested in is, as you say, the need to establish a 24-hour registry with the public guardian and trustee. Would it work without that?

**Dr Dare:** I really do not know how the health care practitioner—and do not forget that the responsibility is on the practitioner who is going to give the treatment or enter into the diagnostic procedures—without that ease of reference is to abide by the legislation that requires him to determine if there is reasonable expectation that the patient has a substitute decision-maker or a power of attorney for personal care or has expressed a wish to refuse the treatment contemplated or has expressed the wish that might override these other instructions to guardians. At best, the result of such an investigation, even if time permitted, would be very speculative without an accurate record somewhere.

**Mr J. Wilson:** Yes. I think of the Via Rail disaster and how emergency rooms must have been swamped with unconscious people. I wonder how the heck you deal with it.

**Dr Dare:** It is easier if they are unconscious, Mr Wilson.

**Mr J. Wilson:** That is true.

**Mr Wessinger:** Dr Dare, I wonder if you could explain how presently, under the current common law, the consent rules work in the hospital particularly with respect to emergency care and with respect to non-emergency care. I particularly draw your attention to the fact that I understand the common law treatment cannot be given without a voluntary informed consent.

**Dr Dare:** I will refer to Carolyn for the actual hierarchy of eligible people to consent on behalf of patients.

**Ms Shushelski:** If you would like me to, I could just elaborate on that now. Just before I say this, I am a lawyer but I am also a nurse, and I worked in the emergency department in downtown Toronto for five years, so I have some knowledge of the practical side as well as the legal side.

The problem existing now is we understand you cannot technically touch them. If you touch somebody, technically it could be a battery. You do need an informed consent to do certainly interventions with the body: surgery, diagnostic procedures where there could be serious material risks, that kind of thing.

I think it is fair to say that when people come into the hospital, what happens now is we are not being sued for giving them a bed bath, we are not being sued for washing the blood off their arm in order to see and to assess what the damage is on a wound. We do go ahead and do certain interventions with an individual. Otherwise, you could not even get to square one to do an assessment, to do a diagnosis. It is absolutely essential that you have the ability to comfort someone, to position him so that he is comfortable. Otherwise, what would happen in an emergency department?

If this legislation goes in as enacted, it says you cannot give care to someone if he is incompetent unless you have a substitute decider to consent on his behalf, which is fine if you have a substitute decider standing there ready, willing and able to consent and you do not have to go through the rigmarole of finding out, is there an existing guardianship, is there a guardianship instrument, is there a power of attorney for personal care, is there a power of attorney? What happens now is you act on the substitute decider's decisions. If they are not there, you do basics. You would never do surgery or anything like that without a proper consent.

I hear what you are saying and I understand, but I think we have to recognize what practically goes on in our hospitals. In order to comfort someone, to not deprive him of humane treatment, you do get on with certain aspects. We would like to see it formally recognized in the legislation that there are certain things you will have to do in order to comfort that person and not leave him in a situation where he is suffering.

**Mr Wessenger:** If I could clarify that for my own perspective, what you are saying is you would like to see something in the act that would permit palliative care to relieve the pain in the situation with respect to patients? Is that what you are saying?

**Ms Shushelski:** I think our brief addresses it. What we tried to do is make recommendations that—it is so complex right now. This is our first attempt at dealing with our membership and putting out a brief. What we tried to do was draw to your attention the existing problems.

We see three areas that need to be addressed: a better definition of emergency treatment; the 12-hour provision is too restrictive, we think, so we would like to see a definition that really addresses the immediacy of a situation. We would like to see some kind of provision that would provide for the practitioners to be able to give necessary care and certainly on the consent of a substitute decider—we in no way want to avoid that—but also the recognition that when people arrive at the emergency department they may not have anyone with them. To find out if the public trustee can consent if there is no relative will take time and we have to recognize that; or even for an advocate to visit

will take time. That interim, that interval must be addressed. If we are not allowed to do that, then we certainly do want to see something that is going to protect our health professionals in hospitals from provisions in the Criminal Code where they would be failing to give necessities of life.

**The Vice-Chair:** I want to thank you for that fine presentation and thank you for coming.

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**Mr J. Wilson:** Mr Chair, while we are changing deputations, I have a question for the parliamentary assistant.

**The Vice-Chair:** By all means, go ahead.

**Mr Curling:** Which one? There are so many of them.

**Mr J. Wilson:** I am not sure. There are three here. When I get Mr Malkowski's attention, I will ask the question.

In the brief by the OHA it does say they understand the government's amendments have been drafted and they have been asked to review these amendments, but to date they have not been made available to the OHA. My question to the parliamentary assistant is, does the government have amendments drafted to this legislation, and, if so, what groups are receiving them and what groups are not receiving them?

**Mr Malkowski:** I would have to repeat that the government has not as yet written any amendments to the legislation. We are first listening to all the presentations in order to be fair, having an open discussion, but the point is that we have not actually drafted any new amendments. I would like to refer to Paul Wessenger, if he would like to add to that.

**Mr Wessenger:** The only thing I can indicate is that I have not seen any draft amendments to any of the legislation.

**Mr J. Wilson:** Okay. You want to stand by those answers, do you?

**The Vice-Chair:** Thank you very much.

R. A. STRADIOTTO

**The Vice-Chair:** The next presenter is R. A. Stradiotto. I want to welcome Mr Stradiotto. If you can read that into the record and then proceed, you have one half-hour.

**Mr Stradiotto:** Thank you. Maybe I should start with who I am. I am a lawyer and I hope in terms of my credibility that does not make me vulnerable.

**Mr Poirier:** It makes us vulnerable.

**Mr Stradiotto:** I have delivered a CV to the clerk; it is quite extensive and I want to touch on it because you ought to know who is speaking. I have been a lawyer for 30 years. I have had a few honours in my life. One of them was Queen's counsel. I have been inducted as a fellow of the American College of Trial Lawyers. But the one honour I would like to bring to your attention, and it is perhaps relevant, is that my governing body conferred its highest award, its medal, upon me. I think it did so for my contribution to the area of education in law in the health field. I am a past president of the Advocates' Society, which is a society of the senior trial counsel in Ontario. I am a past president of the Medico-Legal Society of Toronto, which is a unique society in North America made up almost

half and half of doctors and lawyers. I worked on a number of committees in my time dealing with guidelines to consent.

I am the senior lawyer in a firm in which there is an identified health law group. I am the leader of that group. We have for years been gratuitously publishing a newsletter for the hospitals and the health care community. I just pulled out one of the editions. It happens to be a 1989 edition. I happened to notice that it deals with consent to treatment in the hospital setting, consent to sterilization of an incompetent, a special case, and consent to treatment, which statute applies?

For 30 years my life has been predominantly involved in health care law issues. I have been part of conferences sponsored by the OHA, by various institutions. I have been consulted by this ministry's task force. I have been working on a voluntary basis on amendments to the Public Hospitals Act.

There is not a day in my life when I do not receive an emergency call dealing with consent matters: an anorexic 16-year-old who is at the emergency ward of a hospital, she does not want to be admitted but the doctor thinks that not to admit is life threatening; a 15-year-old who wants an abortion, mother is with her but does not want her to have it; a 15-year-old who requires a liver transplant; a 15-year-old whose state is inconsistent, at times there is competency, at times there is no competency. At times when there is competency, there is a refusal to the treatment modes that are required in liver transplants, at times there is not. I deal daily with these types of problems.

I cannot even begin to quarrel with the government's aim to protect the wellbeing and rights of individuals who because of mental or physical impairments may be temporarily or permanently unable to understand their rights or express their wishes. I am convinced beyond any doubt of the need for legislation to provide the citizens of this province with a coherent body of principle to govern when and how individuals who lack or may lose the capacity to control their lives will none the less be treated with competence, with dignity, with compassion in a way that by any fair or objective standard would be judged to be in accordance with their wishes and best interests.

My difficulty is, and I must confess to this because I encountered it once again last night, that despite the credentials you have before you, despite the benefit that I have had over 23 years of a formal education and close to 30 years in health care law, despite summaries of these legislations that have been prepared for me by my juniors and associates, and discussions I have had with my colleagues, I again last night ran out of steam before I was able to digest the complex processes, the guidelines, the directions, the prohibitions in the labyrinth that has been woven by the interrelated bills before you.

One thing did jump out at me and that is, the families must not have had much input into the process or if they did, they must not have been heard. I want to be clear. I appear before you not as a lawyer, not as an advocate representing a group or an association. I appear before you as a son, the second of 11 children in a family in which the parents are still alive, elderly, their 60th wedding anniversary

was celebrated last Sunday; and for my brother who has Down's syndrome and who is living with my elderly mother and father. The three of them together with their weaknesses and their strengths support one another and manage because of their love, loyalty and respect, but all three at any given time would fit the category of incapable.

I also appear before you as a father blessed with a wonderful wife of 25 years and two boys who are 21 years old, a family that had the gift of a very special son who died as a result of complications following surgery on April 11, 1990, in his 16th year, a son who had Down's syndrome. I want to speak for a moment about him, difficult as it might be, because it is pretty pertinent to what I want to bring to your attention. He was a gift of immeasurable riches which our family was most privileged to enjoy. If it could be said that he was at a disadvantage in this society, it was only in his inability to be self-centred or duplicitous. His spontaneous joy and his zest for life and outpouring of love was disarming. He occupied the centre of our family's activities, bringing laughter and tears of pure joy and infused our family with a bond of love.

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I believe that our family, and many families with whom our family has had contact, who also have persons who are vulnerable in them, was not unique, not unusual, not the exception but the norm. It is in the very nature of the family, at its heart and at its soul, that it will love, support and nourish its members and the response is magnified in proportion to the need of any particular member. I had the pleasure of observing the consistency and the intensity of the love my two sons and my wife had for my son who was handicapped.

Now where does all this fit in? My son had a problem, as well as being handicapped in the mental sense. He had an unusual condition known as tetralogy of Fallot and a mitral stenosis. As a result of these conditions, in his life he had to undergo a process of catheterization seven times. He had to undergo two major bypasses, the first when he was two years old and the second when he was five years old, open-heart surgery in 1981 with a valve implant; he had to be reopened and it all had to be done again in 1985 and a third time April 11, 1990. He did not survive that one.

I look at this legislation and what it would have done. I have the benefit of the background and training to look at it and I have difficulty understanding it. When my son had to go to the hospital my wife and I would prepare him, particularly my wife—you have to understand that these people have a tremendous capacity for certain things and a tremendous lack in other things. It is not always consistent. There is an awareness and a lack of awareness.

When you take him to a hospital and he confronts a health care provider, the health care provider may think he has demonstrated a wish not to be treated when he was under 16, and he could do that. When he was over 16, or thereabouts—and there was never an emergency, by the way. He was not rushed to these processes because they were emergency situations. There were periodic times when his condition and his colour would show that electively

it might be time to renew the valve. So we do not fall into the emergency provisions.

Any health care practitioner talking to my son Shane would probably conclude that he was incapable. A great deal of that may be as a result of the difficulty to communicate. Under all those circumstances we trigger this legislation. Bring in the advocate. Unless my son refuses—and how a stranger would know that he is refusing or not leaves me in pure wonderment—this whole process is invoked. I do not want to say too much about this, but I really have a problem of understanding the questionable premise on which this legislation is in part based, that an advocate shares the status by his condition and therefore is somehow specially gifted to have insight in judgements in these matters, just by that simple fact.

I am concerned about what intimate time-worn contact the advocate has had with the vulnerable person that qualifies him or her to interpret ahead of family or friends, what specialized training, what professional contact. The advocate is neither a family member nor a friend particularly. On what basis can advocates presume to have this greater understanding of and greater sensitivity to the vulnerable person's wishes and needs than do families, friends or long-time health care givers who have come to know him or her, as many of them knew my son and had come to understand him?

Please understand that I am not against the system of advocates. It is no answer to me. You cannot begin to justify what this legislation does by putting to me the questions, "What about those who fall between the chairs? What about those who don't have a family to support them?" as I and my son have been benefited. Why do we not deal with that? Why do we not direct our efforts at that? Why do we not establish our target and pass legislation dealing with that? A system of advocacy, fine, but that is not all this has done. This has gone far beyond keeping everybody in after school because somebody talked.

It is not an answer to me or my wife to say, "Why didn't you solve your problem and establish yourself as an appointed guardian or go through the board process and become an official representative?" It is not that simple. I wanted my son to have the right as he matured, with the potential he had, to give him all the scope of making his own decisions. Why would any government ask my wife and me to go through processes like this with the costs incurred and what it is doing to society? What an Orwellian concept. Then you remember that you are dealing with an individual who had tremendous capacity and was not consistent in every facet, not even on a day-to-day basis, and you ask us why.

This is my plea to you to consider what this legislation does in such an unnecessary fashion. This legislation is an affront to the family. Its attitude, tone and approach are an affront to competent, caring health professionals and sensitive, loving families. The legislation demeans the family; unintentionally, but it does. It emanates an aura of distrust, a lack of faith and belief in the values and integrity of the family unit in our society. The process will unnecessarily become a source of great—"irritation" is hardly the appropriate word, and at a time in a family's life

when it is filled with stress and grief. What government would want to do that?

You have a purpose, you have a need. Father Sean enunciated that, but please do not tell me he wanted this. I was quite familiar with what he wanted. This is not what he wanted. This is not an answer. You have heard speakers before you. I read this and I am always amazed at what society does to itself. It passes legislation in which we will need a lawyer every 10 feet as we walk down the street. Why do you give us such authority and strength? Why do you compound the costs? This is a godsend to the litigation bar. It is an absolute gift, a source of activity that will—I will have to double my department, there is no doubt about it, in no time at all, at a time when the health care system's need for resources and funds is so painfully, desperately obvious to us all. Please send it back. It is overreaching. It is an overreaction. It is overkill. It is not what Father Sean O'Sullivan had in mind. Thank you.

1110

**The Chair:** Thank you. Briefly from each caucus, about three minutes.

**Mr Poirier:** What the hell can I add, anybody being insensitive to that. I am sure Father Sean, seeing this, must be really turning upside down. How the heck you can go from a noble principle and screw it up this way, and coming up with your background to see this, obviously you are not coming here to waste your time or our time.

I appreciate your coming forward. I can only hope the government is going to be sensitive to that, because we certainly are. Like you, we like the principle. We recognize that some people are falling through the cracks. We should address our energies to that. But as I said, if even you as a lawyer can come here and tell us this is a godsend for litigation, who the hell can tell us better than that? Eight ears on that side, take it away.

**Mr Curling:** I want to commend you for coming forward with that very sensitive presentation. Actually I hope the government and the drafters of the legislation realize that the legislation has intruded into the family, which is the basis of any society, where love starts, where love is thwarted. I know the government party itself has stated that it itself is one of the parties that believes in the family. I think that, as someone said, this is a good idea, but it took a wrong turn. I hope they are quite sensitive and do not destroy the family in this process.

**Mr Stradiotto:** If I may just add a word, if we all had this choice put to us, who ultimately should make the decision that would best express the wishes and interests of persons who are vulnerable, a judge, a physician or a medical committee, an advocate or a public trustee, or members of a loving, caring family in conjunction with their medical advisers, spiritual advisers or advisers of their choice, I hope it would take everyone in this room about half a second to say: "Surely the latter if it is available. Let's encourage it and, when that is not available, let's make what is required available." That is not what this legislation does. It does incredible harm to that latter group. That latter group is the group in which the vast majority of people we are trying to help exist. We can deal

with the others much better than those who are getting added in this legislation.

**Mr J. Wilson:** I do not have much to add except to indicate that I do not think there was anything in your brief that I or my colleagues disagree with. Many of the arguments you put forward we have heard and have been acting on. In fact, I have tested some of these arguments with my own constituents. They are ashamed that I am here sitting on a committee every day, having to spend \$30 or \$40 million, when our hospital beds are being closed in the riding. I have not had one constituent come up to me telling me this is a good idea by any means whatsoever. Most of what I have heard has been negative.

I do not even know if I believe in the principle any more, because we have had government after government pretending we have such a great social safety net, pretending we have resources in place in the community to look after people's basic health care needs. We find ourselves here not addressing those problems, but dealing with principles of advocacy and what I see as a huge expenditure. We are trying to play ball, though, because I think the government has made up its mind that this bill is going through in some form. We will certainly keep your concerns about the family particularly in mind in introducing amendments along the way to try and bring the bills around to a more reasonable position.

**Mr Winninger:** Mr Stradiotto, thank you for coming here today. I note that you have been practising since 1962, so you have considerable experience. You may recall some of the challenges posed over the last 30 years because we did not have a power of attorney for personal care in these kinds of situations.

I would like very briefly to explore with you a couple of scenarios that you have covered. We have two broad categories: one where there are family supports and one where there are not. I do not think you would disagree that where there are not family supports there is a role for the advocate, perhaps an even more enhanced role for the advocate than when there are family supports, and also an important role for personal guardianship in that situation. Would you agree with me in that category?

**Mr Stradiotto:** I might even go further. I might say that even in the context of family there may be a role of the advocate, but I think the advocate has to first cross the threshold of establishing a *prima facie* need. The trouble with this legislation is that it is based on an assumed distrust. I agree with everything you say, even in the context that we can find abuse within a family. Families do not always work.

**Mr Winninger:** Now in the second broad category where there are family supports we might have three sub-categories: one where the vulnerable person lacks capacity to consent to treatment or capacity in general, one where the person has capacity and perhaps another case, which might represent the case of your late son, where capacity might be somewhere in between, partial capacity. Now let's say the family supports are there in all these cases and you have someone who is incapable of making decisions for himself or herself. You as a family member would be a

preferred guardian. As you know from the legislation, you can apply to the court and be appointed a guardian for the personal care of your son if he lacks capacity. If, on the other hand, he has capacity, sure, the advocate will come in—at his request, if he wants to see the advocate. That does not in any way diminish your ability or the ability of your family to provide care, does it?

**Mr Stradiotto:** Why would you ask my wife and me to go through a legal process to take care of our son in the circumstances I have illustrated to you? I have no other answer than to say to you that I think that is a totally unnecessary expense on society, a totally unnecessary imposition on the affairs of a family that is, we think, taking care of our son. Why do you ask me to do that? Next week are you going to ask me to do that for my mother?

**Mr Winninger:** No. Because your late son wanted to see an advocate, why would you deny him that privilege and protection?

**Mr Stradiotto:** Whoever suggested I would?

**Mr Winninger:** That is all I am asking.

**Mr Stradiotto:** You are asking me to take a legal proceeding. I do not understand what has happened to this government's concept of society if it has decided that my wife and I, in the circumstances I have illustrated to you, should be compelled now to go and take some formal legal proceeding in managing the affairs of our son and our family. Next week for my mother and the week after for my brother and next month for my father?

**Mr Winninger:** That is your option.

**Mr Stradiotto:** That is not my option.

**Mr Winninger:** No one is forcing you to seek guardianship.

**Mr Stradiotto:** The consequences in this legislation are formidable if I do not.

**Mr Winninger:** It sounds to me like you are agreeing that if your late son had wanted to see a guardian, you would not have stood in the way.

**Mr Stradiotto:** Absolutely not.

**Mr Winninger:** So what is the problem with advocacy legislation?

**Mr Stradiotto:** There is no problem with advocacy legislation. I have told you, I thought clearly, that I support it entirely. I do not see why this advocacy legislation is necessary in the form it is drafted, that is all. This advocacy legislation is gross overkill and is absolutely a downer for the family structure.

**Mr Winninger:** If your son was content with the care your family was providing, he would not want to see an advocate anyway.

**Mr Stradiotto:** I thought I made the point that when I presented my son to a hospital, under this legislation the doctor speaking to him would look at me and say: "He's incapable. I can't touch him." It triggers the process. It is unavoidable under this legislation. That is unnecessary, I thought, and I was trying to point out why to you.

**Mr Winninger:** If he is incapable—

**The Chair:** Thank you, Mr Winninger.

**Mr Winner:** One last question, one last important follow-up.

**The Chair:** Mr Malkowski will have to forgo his time then.

**Mr Winner:** If he is in fact incapable of making such decisions.

**Mr Stradiotto:** In whose judgement?

**Mr Winner:** You just said "if the doctor finds him to be incapable of consenting to medical treatment." Is it not appropriate that, if you are going to decide on his behalf what kind of treatment is meted out to your son, there be some kind of legal safeguards, formalities in place, ie guardianship, to ensure that substitute decision-making complies with those safeguards?

**Mr Stradiotto:** I cannot help but say bluntly that I do not understand why you would possibly think that was necessary. To think that is what is happening in our society appals me.

**Mr Winner:** You have defended doctors.

**The Chair:** Thank you, Mr Winner. Mr Stradiotto, on behalf of the committee I would like to thank you for taking the time out to give us your presentation today.

1120

#### TORONTO MAYOR'S COMMITTEE ON AGING

**The Chair:** I would like to call forward our next witnesses, from the Toronto Mayor's Committee on Aging.

**Mrs Smith:** Good morning, ladies and gentlemen. I am Harriet Smith and I am chair of the Toronto Mayor's Committee on Aging. I have brought along with me a cohort of mine, Christine Hurlbut, who is going to speak to the other three bills. I will speak regarding the advocacy bill. Christine is the director of the student assistance program for seniors in north Toronto.

The Toronto Mayor's Committee on Aging is—do I dare use the word?—an advocacy group that is composed primarily of seniors, but we do have many younger people on our subcommittees who help to advise us. These people are working with seniors and on behalf of seniors. Christine is one of those.

First of all, I would say basically that we have studied these bills and we find the Advocacy Act commendable for its intent. However, we do have a few things we would like to point out to you, most of which are sort of house-keeping items. Let's say that in principle we agree with the intent of the Advocacy Act.

One of the first things I would like to see expanded in this act is the definitions. The Advocacy Act is intended for persons who are vulnerable and I think we need to have a little better definition of "vulnerability." We need better-defined "physical disability," "mental disability," "illness" and "infirmary." These tend to be very open-ended words and we would like to see them more concisely defined.

Second, we would like to see assurance of senior representation on the commission. TMCA would like a guarantee of proportional representation of seniors, that is, persons 65 years and older on the commission, as well as on the advisory committee.

Back in April 1991, the Honourable Elaine Ziemba, Minister of Citizenship, stated to the Legislature:

"Our next step will be to set up an advocacy commission which will operate at arm's length from government. In keeping with our commitment to community involvement, we will form a broadly based advisory committee representative of the disabled and the senior citizens' communities. This advisory committee will nominate candidates to serve on the commission. The commission will also be representative of the communities it serves."

As this bill is presently written, there is no assurance that senior persons will be adequately represented on the commission.

I would like to point out that TMCA strongly advocates that more seniors be used on public boards. There are many of us who are experienced from our past careers. We still have all our faculties, we have time and we have intent and we would like to be used in our older age. I would strongly suggest that seniors be used not only on this public board, but that they also be considered for more public boards. It is our way of paying back our fellow members of society for our good fortune.

TMCA would also suggest that somewhere in the act or in its rules and regulations there be described a system for staggering the initial terms of office. Perhaps this will come in the rules and regs, but we would like assurance that this will be initiated smoothly. It will indicate a perpetuation of the committee without a sudden gap of experienced persons. There should also be rules regarding numbers of absences at meetings to assure adequate interest, continuity and quorum.

Another item in regard to terms of office or functioning of office, considering that disabilities can be cyclical and sometimes inhibit the activities of an individual, is that there should also be some provisions made in designing the membership of the commission to ensure that there is a functioning commission. We are suggesting that perhaps alternatives should be named. There will be times when disabled persons on the commission and even seniors who are presumably healthy will have difficulty in attending, yet there should be adequate attendance to assure proper functioning of the commission.

Last, there is one thing we would hope: that those people who are entrusted as advocates will strive to develop honest, friendly relationships with those persons they represent.

**Ms Hurlbut:** I was part of a subcommittee which worked on Bills 108 and 109, and very briefly on Bill 110 because of its lack of content, as far as we were concerned. We felt again that it was high time these bills came to fruition. The government in fact was trying to put the concept of living wills and the whole system of potential guardianship into action, but we felt again that there were some holes and some problems with the legislation as it now is consistently.

We are pleased that the bills do provide scope for the individual to make decisions about personal care while competent and have these decisions stand, even though they are not perhaps in written form, and that wishes be recognized as well. However, both in Bills 108 and 109 we

felt uncomfortable with the concept that one needed to be 18 to have guardianship of property but only 16 to be able to have guardianship over personal care. We realize of course that people can be parents far under 16 and therefore should have some say in what happens to their young children, but we are just generally uncomfortable with the issue of a 16-year-old having this kind of power.

As Harriet said, we also hope that the advocates will strive to develop honest, friendly relationships with those they represent. It is of course very difficult to put into legislation, as it is difficult to assume by any kind of legislation, that a family is going to be a loving, concerned unit and have the best interests of its members who are incapable at heart at any one time.

Bill 109 also states with some strength the concept of informed consent. However, we also suggest the inclusion in this bill of the following: first, a requirement to give ongoing information to the patient or the patient's representative or the advocate; and second, an indication of the way this information is to be passed on, and possible penalties for failure to give the required information. If a person is having someone's life literally in his or her hands, I think being unable to secure proper and continuing and updated information from the medical community is certainly a large roadblock to making a good decision.

Members of our committee noted having a difficult time gaining updated information from the medical community when a member of their own family was in hospital. Also, section 22, at the very end of Bill 109, protects certain health professionals who give emergency treatment without consent. We felt quite strongly that this should be extended to include ambulance workers, paramedics and others who may in fact be the first people who have to make a decision on the spot about someone's care in an emergency situation.

1130

**Mr J. Wilson:** Thank you for the presentation. At the end of your presentation you did mention ambulance workers. It occurred to me yesterday. The question should be asked I guess to legal counsel. Under Bill 109, how does it work in the ambulance in terms of their being required to get written consent? The ambulance staff would not have nearly the resources that the people in the emergency room or the attending physician might have, although that is dubious at this point too. I am sorry to take up your time, but I think it is an important question.

**Ms Bentivegna:** There is intent, because the act allows for a prescribed class to be added, to put in paramedics or ambulance attendants so that they could therefore use the same rules of consent. If there is an advanced medical directive, that can also be respected if they know of it, let's say if the person does not want to be resuscitated.

**Mr J. Wilson:** How do they know? They just make every reasonable effort to find out? Is that the point?

**Ms Bentivegna:** Exactly.

**Ms Hurlbut:** If I might add to that, on our committee we had several cases of people whose parents had perhaps indicated they did not want to be revived, who were rushed from the home to the hospital where they might have died

a fairly peaceful death but the ambulance workers revived them two or three times on the way and this just prolonged it. Again, there was perhaps a lack of informed consent and I realize that ambulance workers have their job to do, but it is a tricky situation. We felt they should at least be covered by the terms in this act.

**Mr J. Wilson:** Thank you. Both of you mentioned I think quite correctly but perhaps idealistically that it was your hope that advocates would have a strong personal relationship. I guess part of our concern in this area is that you would need several hundred, I would say, more advocates than are currently being envisioned by the government to actually do that. When I think of the hundreds of social workers or welfare case workers we have and their inability to see their clients, some never see them in an entire 12 months, this could be a very expensive system. To work right, I agree they should get to know their clients well in order to be able to express the wishes of those clients.

But I wonder, as advocates for seniors—I do not think we can ignore economic realities of today and I do not think they are going away. Things may get better, but the underlying ability to properly fund our health care system in the future is now in question. It is in question now and certainly will continue to be throughout the 1990s. Health care is definitely the issue of the 1990s. How high a priority is bringing in an advocacy system which may cost a great deal of money versus ensuring that the proper community services are there to look after your health care needs? It is a value judgement. I have groups tell me that no matter what price, this system has to go in. I have told them something has to give.

**Mrs Smith:** Can I suggest that you put in place the legislation? Under the financial restrictions of today you can start small, but we know there is a need out there for advocates. At least it will be available for some. It may not be available for all, but at least it will be available for some, and that is better than nothing.

It so happens that we originally wrote this brief back in September, and my opening paragraph in writing this was, "We commend the government for the development of this legislation but wish to emphasize that the legislation must be backed up with adequate budget and personnel for the office of public guardian and trustee to administer it." That goes for the role of the advocates too.

Of course, we know that economic times have changed, but I personally feel that now that you have the momentum on the Advocacy Act, you should not lose that momentum, but keep it rolling and get it into law. If it has to simmer with only a few benefiting because of limited budget, it is still there and can be expanded when moneys become available.

**Mr J. Wilson:** That is interesting, because we have had other groups saying that if you take half measures, you may cause more harm to the system.

**Mrs Smith:** I am expressing a personal opinion when you ask this question.

**Mr J. Wilson:** Sure. I appreciate that too.

**Mrs Smith:** That may well be, but you know how long it takes to get legislation through. You are looking at a loss of two, three or four years.

**Mr J. Wilson:** Especially when it is so badly flawed.

**Mrs Smith:** I would hate to think that we have to lose this momentum we have now.

**Mr J. Wilson:** Okay. I appreciate your frankness.

**Ms Carter:** I would like to thank you for your constructive and concerned criticism of our legislation. You have certainly come up with some positive suggestions.

I am just a little concerned that you are not satisfied with the representation of the over-65 group, because in section 15 of Bill 74 there is a list of eight categories of people who would be included in the appointments advisory committee, and that does include organizations representing persons 65 years of age or older. You are one of the eight categories. Of course, being elderly is not itself a disability, and you do not necessarily have any life knowledge of disability because you get elderly. I hope not; I am getting up towards that myself. Also, of course, it is true that elderly people will be or could be represented in the other seven categories, because they are just as likely to come under the other categories as any other person might be. I am just a little concerned that you are not satisfied with that representation.

**Mrs Smith:** We would just like assurance that there will be adequate senior representation.

**Ms Carter:** I see no reason why there would not be under this.

**Mrs Smith:** Okay. Sometimes there is a difference between what is written and what will become practice.

**The Chair:** On behalf of the committee, Mrs Smith and Ms Hurlbut, I would like to thank you for taking the time out of your busy schedules to give your presentation this morning.

1140

#### FAMILY SERVICES CENTRE OF SAULT STE MARIE AND DISTRICT

**The Chair:** I would call forward the people from the Family Services Centre of Sault Ste Marie and District. Good morning. Could you please identify yourself for the record and then proceed.

**Ms Tasz:** My name is Mary Tasz and I am an adult protective service worker with the Family Services Centre of Sault Ste Marie and District. There are currently three of us working out of our office.

The adult protective service worker is a transfer payment service, and I am sure most of you know that. I think adult protective service workers have been pretty vocal in the past two years in trying to get our message across to the Advocacy Commission. Our program began in 1974 after a study commissioned by the government determined that individuals returning to the community required supports to live independently. The family services centre in our area has sponsored the adult protective service worker program since 1978. I have been with the program since

1983. With deinstitutionalization, advocacy has become an integral part of this position.

I have been sitting here listening to the people speak all morning. Most of the clients we work with have no family that we can rely on—we wish we could, but we cannot—in helping to make the decisions, so I guess we are coming across from a different perspective. I am usually the person who helps the clients make the decisions.

On behalf of the APSW program, we are pleased that the Advocacy Act may finally come into being. The family services centre has actively been involved with previous studies, ie, You've Got a Friend and the Fram report. We think both have helped lead to this act.

Some of the provisions in the act we think are positive, including advocates' access to records, their clients and facilities. We feel that will provide for better service and care for our clients. This bill presents a community development approach in the provision of advocacy services and it promotes self-advocacy. As adult protective service workers, we believe that is very important. It is a culturally sensitive bill, one which will aid individuals to achieve their independence.

Consumer control of the Advocacy Commission is positive. This agency supports an open-ended definition of who will require advocacy services, thereby preventing agencies or services from misleading people. It will be possible for vulnerable people to have an independent advocate with the power to investigate possible abuse. This agency also supports a model that ensures independence of advocates from specialized service-providing agencies or ministries.

We do have some comments and suggestions. The Adult Protective Services Association has submitted a brief, and some of our thoughts may be along the same lines as theirs.

Subsection 5(2), a housekeeping item maybe. The board may number from seven to 13. We think the upper limit is more viable if we want provincial representation. With seven people you are not going to get the provincial representation.

The Advocacy Act is selective in utilizing the existing advocacy system. We see that the psychiatric patient advocate program is moving over and that the APSW program is not moving over at this time. It is suggested that this program remain with the Ministry of Community and Social Services. This is the same ministry that provides and funds many services which the adult protective service worker has to access on behalf of his or her clients.

I would like to give you some examples of the conflict. Recently, the family services centre took a stand not to show client files to MCSS until we had consent from our clients. This disagreement lasted for approximately four months before it was resolved. Since this program is 100% funded by MCSS, the ministry had the option of withholding the budget for 1991-92 until this agency complied.

Family services took this stand only after consultation with our clients, the president of People First, the Advocacy Resource Centre for the Handicapped, child and family services advocacy and the Ontario Association for Community Living. The general consensus was that by

showing client files we were breaching clients' trust, and that there must be better ways to complete a financial audit of our program. In fact, one client told me that if I were to show their files, I should not have the job I have because it was their personal life that I was showing.

These difficulties with advocating also occur in the residential and vocational programs. It is difficult to advocate within a system that has the same sponsorship for service providers and the adult protective service workers, especially when the adult protective service workers are working with clients to meet their needs. This places us in a position of advocating against the same system that provides the funding.

The program supervisor of the district office with the Ministry of Community and Social Services is often the same program supervisor for the specialized service agencies we are attempting to secure services from. Often we have to advocate against these same service providers.

In Sault Ste Marie and district, rationalization of services for the developmentally handicapped is authored by MCSS, and this became an issue. Our agency publicly took a position that the APSW program should not be included because of the potential for conflict of interest. Immediately following a public forum on this topic, ministry staff suggested to this agency that we should review our contract and other ministry-funded programs within this agency. This type of intimidation would certainly stifle true advocacy in most agencies.

We believe that resource coordination and case management, especially in rural areas, is a primary step to identifying advocacy issues, and that the two cannot necessarily be separated. Having stated that, a colleague called from Manitoulin Island in the last week and her comment was; "Don't forget to say this, because I work with the native population, and if they don't trust me and if I don't do some case management, I can't advocate on their behalf."

However, we also recognize that there will be times when the two must be separated. We see that the Advocacy Act would be a resource to this program when advocating for some individual and systemic issues, but at the same time they will complement each other. This could be seen as a bonus, because some individuals are concerned that advocates will not be taking a case management function. Because of this blatant conflict of interest, the family services centre recommends that the Advocacy Act include provisions to have the APSW program transferred intact to the Ministry of Citizenship.

The proposed bill has no provision allowing for emergency entry to facilities. I heard people arguing the other side of that this morning. As it stands, if an advocate is refused entry into a facility, a search warrant must be obtained. There should be a section dealing with emergency entry. The family services centre takes this a step further and recommends that access to clients within these facilities be available as required.

This bill does not explain fully under which circumstances non-instructed advocacy becomes necessary. It is important for advocates who locate individuals who are unable to express their wishes to be able to take whatever action is necessary on the client's behalf to restore some

degree of safety, security and wellbeing. We also recognize that there are needs for checks so this is not abused by the advocate.

The definition of a "vulnerable person" in section 2 fails to protect the most vulnerable people in Ontario. It excludes those who are unable to express their wishes.

The act does not provide for a minimum number of regional offices. This should be included as part of the act. Northern communities have little faith in commissions that make decisions from Toronto. Regional offices are important for advocates to work out of, but also in order for the community to be aware of their presence.

This act empowers clients and their advocates. It does not require the government to respond, however, to concerns raised on a client's behalf. We would like to recommend a provision within the act which ensures that the government's response to concerns raised by advocates within the commission occurs within a specific period of time.

The act ensures that vulnerable adults have the same rights as other adults. Within the community, this act makes no specific mention that advocates will take action to protect their clients from abuse and neglect, and this needs to be stated. However, having stated this, often community resources are sadly lacking for developmentally handicapped adults who have been abused. We must be careful that upon investigation the individual will be removed to a safe place, or we may be setting that individual up for increased abuse and neglect upon the advocate's departure.

The commission does not have a provision made for appropriate evaluation of community-based advocacy efforts. Advocacy services must be accountable. Therefore, a system needs to be in place prior to implementation of the advocacy program to allow a commission to suggest that funding be withdrawn from an agency, group or organization providing advocacy services if standards are not maintained—accountability.

The family services centre has some concerns in a situation where a vulnerable person indicates that he or she does not want the advocate to stay. Subsection 21(3) places an obligation upon the advocate to leave. Many of the developmentally handicapped clients and physically disabled clients we work with will make a request such as this, if they are told to by someone else. Many of our clients have learned to do what they are told and not to even question, even if they do not agree. Questioning sometimes leads to worse consequences, especially if you are in a wheelchair and somebody has to provide the services to you. We are setting that person up. It is family services centre's recommendation that the Advocacy Commission look into this for an amicable solution to this concern.

#### 1150

Clauses 24(3)(a) and (b) should be deleted. Clients have every right to know what is or is not in their file.

I would like to speak to Bill 108, the Substitute Decisions Act, and Bill 109, the Consent to Treatment Act. Before any of these acts can occur, it is important that Bill 74 be in place and tested to determine if there will be a need for guardianship legislation.

The proposed office of the public guardian and trustee needs to have services in place to fulfil the mandate of Bills 108 and 109. As it stands now, we have yet to meet a public trustee worker, although there is a person responsible for at least 15 clients we service in a local nursing home. As workers in this field, we are still not certain of their role and how they interface with the client.

The new office will need to have significant representation for all groups, and must be more service-oriented and accessible across the province. North Bay is closer to Toronto than it is to Sault Ste Marie, but the homes for special care worker works out of North Bay. The public trustee office has no presence at all in our community. When a client dies, they have to die between 9 and 5 because that is when the public trustee's office closes. There is no worker available after that. I bury that person; the public trustee's office does not. And you had better hope that they die from a Monday to a Friday, because we do not have a presence in our community.

In Bill 108, in speaking to accessibility to the court system, the proposed substitute decision-making legislation depends heavily upon the court system to ensure that an individual's right to appeal is protected. Efforts need to be made so that a person deemed incapable is guaranteed access to an advocate within 24 hours, and this access should not be limited.

This agency does have concerns about Bills 108 and 109. We recognize an improvement over the current laws governing mental incapacity issues. The concern lies with the impact, or the potential impact, of this legislation on vulnerable persons' personal rights regarding unnecessary intervention and access to support. It is important whenever possible that vulnerable people be able to maintain their decision-making power.

The family services centre is committed to prevention and advocacy. We applaud the act in terms of providing advocacy for the elderly, physically disabled, developmentally handicapped, and head-injured and brain-damaged individuals. As adult protective service workers, we find that many unserved clients, especially the physically disabled, elderly and head-injured, would benefit from a program such as the APSW program. The Advocacy Act takes it one step further away from conflict of interest of funders and provides legislative authority so that advocates can do their job.

Often in the course of our job, we find that other special needs groups require many of the same services that we provide for the developmentally handicapped. Regardless of whatever disability a person may have, a vulnerable individual does require an advocate. It is important for the Advocacy Commission to ensure that this program be independent. It should be within a free-standing organization because its role is advocacy. Otherwise it could lead to a conflict of interest, something that adult protective service workers experience on a day-to-day basis, being funded by the same ministry we have to ask services from.

We would like to reiterate that this act is a positive step in advocating for the rights of vulnerable adults. The APSW program would complement this act by being

transferred intact from the Ministry of Community and Social Services to the Ministry of Citizenship.

**Mr Curling:** Thank you for coming in and making this presentation. As I was reading your presentation, some things come to mind: the proper definition of "vulnerable person," what that is. It seems to me that you are not quite sure how the legislation defined for you what is a vulnerable person and when did they become vulnerable, because people are sometimes vulnerable continuously, and for some, certain hours or certain conditions make them vulnerable. Do you think that this legislation helped you to understand more who is vulnerable and when they are vulnerable?

**Ms Tasz:** I think my client should help me to understand who is vulnerable and when they are vulnerable. The legislation has defined it a bit better.

**Mr Curling:** I see. On page 7 you say, "Subsection 21(3) places an obligation upon the advocate to leave." I understand you are saying here that if that the vulnerable person, so defined, would have an advocate, he could say, "I don't need that advocate any more." Am I understanding you to say that the law should specify very much so that advocates should have a right to stay?

**Ms Tasz:** I am saying that in some cases we have clients who are told to say certain things by other people and one of those things may be, in a crisis situation, that they do not need an advocate. Maybe they have been sexually abused in that home and that person is telling them that they do not need to see the advocate and they do not want to see the advocate, yet they do. But because they are told to say that, they will say that. I am saying we need to be aware that those types of things happen, especially with the developmentally handicapped, who have learned over the years to do what they are told to do.

**Mr Curling:** You are saying whether vulnerable people want an advocate or not, they would have an advocate.

**Ms Tasz:** No. I am saying there has to be a system in place to ensure that an advocate is available to that person, and if it is questionable as to whether or not they need an advocate, there has to be some system in place. I am not sure what that system will be. I have worked in this position for nine years and I have had clients tell me that they did not want to see me, or have not told me what has happened, yet at a later time they will tell me, and I know that something is going on.

**Mr Curling:** It is a change of position.

**Ms Tasz:** They are afraid, so because they are afraid, they will not say something.

**Mr Curling:** I am glad you mentioned the fact that there are advocates around today. Yesterday some of the members here felt there were no advocates paid by government. There are many advocates paid by the government and millions of dollars being spread out.

**Mr J. Wilson:** A witness made that point, not a member.

**Mr Curling:** Yes, a witness made the point. Actually, some members confirmed the fact. I wanted to restate that there are many advocates around today paid by the government to do the job.

**Ms Tasz:** Although MCSS would say that adult protective service workers are case managers.

**Mr Curling:** The last question I have: Do you see that this advocate law helps the family, enhances the family, or do you see it somehow put a sort of a mistrust on the family system to say that your family may not be the best people to look after you, but an advocate?

**Ms Tasz:** I think the family has to be the primary person to take care, if they want to take that on. What I am finding with my client group is that the parents have wanted to take responsibility for their children, but as the parents are aging, the brothers and sisters do not necessarily want to take on that responsibility.

**Mr J. Wilson:** Thank you for your presentation. You began quite correctly, I think, by discussing conflicts of interest that are perceived or real in the system now. You also began your brief by being very supportive of the Advocacy Commission and the fact that the majority of its members will be made up of vulnerable people.

In this legislation, as I see it, the government is taking two important steps that are unprecedented in the province. It is setting up an arm's-length commission which in itself, under law, will be biased and partisan. Then it is saying, in the powers of that commission and in fact in its mandate, that it is to help effect change at the political level.

You have discussed conflicts of interest between protective service workers, for instance, and the same funding agency. Do you not see a conflict of interest here in terms of its being funded by the government but we are going to have people who are there to effect political change, and indeed to help vulnerable people set up organizations which I assume will also advocate for change?

**Ms Tasz:** I think we would like to see it as a free-standing agency without government controls. However, when you look at a ministry that might be funding the program, the Ministry of Citizenship is the ministry we would support, because it is not providing the services to clients that we would have to access, so we believe there would be more support.

**Mr J. Wilson:** The question has been raised—I do not know whether you would agree or disagree; I suspect you might disagree—that members of the Advocacy Commis-

sion, because of potential conflict at the political level, should not be allowed to participate in political parties or political campaigns, and that this should be part of this legislation. For the first time in the history of the province we are setting up an arm's-length body that has a bias, not necessarily political, but has a bias in terms of service groups, that has in law a mandate to effect political change, to bring about political solutions. I cannot think of a more direct conflict of interest ever stated in a piece of legislation.

**Ms Tasz:** I would like to see the program piloted—this is a personal stand—and tested in a few areas, and then come back and really look at it.

**Mr J. Wilson:** That is an interesting suggestion, because that has been brought to us too, that perhaps we should be doing a pilot project, not across the board, to see what happens. In fact, some of the larger hospital organizations would, I think, support that.

**Mr Morrow:** I want to thank you for taking the time out to appear before us today. I just have one really brief question so I can clarify something for myself. Do all APSWs play the same role across the province?

**Ms Tasz:** No.

**Mr Morrow:** That is a quick answer.

**Mr Malkowski:** Just two brief questions. First of all, do you agree that we do need the Advocacy Act in place, even though, for example, you do some advocacy as an APSW? My second question is simply what proportion or percentage of your work is case management versus actual advocacy work?

**Ms Tasz:** Yes. I would like to see this Advocacy Act in place. The percentage of my job, I am not sure. I really could not give you an answer, maybe 50-50.

**The Chair:** I apologize for the background interference here. It made it a little difficult hearing your presentation, but on behalf of the committee, Ms Tasz, I would like to thank you for taking the time out and coming such a long distance to give your presentation.

This committee stands recessed until 1:30 this afternoon.

The committee recessed at 1203.

## AFTERNOON SITTING

The committee resumed at 1341.

FEDERATION OF ONTARIO  
FACILITY LIAISON GROUPS

**The Chair:** I call forward our first presenters, from the Federation of Ontario Facility Liaison Groups. Good afternoon. Would you please identify yourselves for the record and then proceed.

**Mrs Paproski:** I am Margaret Paproski, president of the Federation of Ontario Facility Liaison Groups. Janet Allingham is our secretary and also president of Huronia Helpers. Peter Delsnyder is our treasurer and vice-president of our Oxford regional centre.

In leading off, I have submitted a brief which I will speak to. It is long and there is some extraneous material, background material I thought would be of interest to members when they come to the recommendations.

In general, the federation is very pleased that the government has entered upon this initiative to provide advocacy, guardianship and support to vulnerable people. We will be speaking specifically to Bill 74, the proposed Advocacy Act; Bill 108, the Substitute Consent Act, and just in reference to the amendment to the Developmental Services Act, Bill 110.

We represent some of the most vulnerable people in this province; that is, adults who have a lifelong condition of mental retardation and who, because of the severity of their disabilities and the lack of community services, live in institutions.

None of us here has a legal background, so we are, as I assume many of the MPPs are, looking at a very difficult and complex area. We just want to present our concerns and some of our perspectives as to how the legislation might be improved to reflect our concerns.

One of the dilemmas we feel we face in these pieces of proposed legislation is the lack of recognition they appear to give to families and long-standing friends of people who are incapable of giving consent or providing direction. All the pieces of legislation to which I refer have clauses relating to the vulnerable person giving consent or being able to direct. Our people function at a much lower level than that and, although they may be able to indicate what they are pleased and happy with, they may not understand the long-term implications of certain decisions. That is one of the most important pieces we see lacking: These people seem to be omitted from the proposed legislation. It is my understanding that at one time there had been a clause relating to the advocate taking advice or consulting with significant others—that is, family or long-standing relationships of these people—and somewhere along the line that has been disposed of. We suggest that it should be reincluded.

Many of the people we represent do not easily develop trusting relationships. They can and have developed defensive and coping mechanisms which can be very difficult to break through to reach them and to understand what they are trying to convey. Therefore, to have an advocacy system

which enables an advocate to see them on a very infrequent basis is not necessarily going to have a positive influence or effect on their lives. They will perceive these people as strangers, possibly as not looking after their best interests, and, in the case of some of the people I know, will withdraw from having anything to do with them because they are frightened of strange and new situations and people. Therefore, we are a bit afraid that for these particular people the Advocacy Act will provide a cloak of legitimacy for a bureaucratic system to impose maybe a political will on the type of services and supports they should be receiving.

It is interesting that one of the criteria for admission to an institution is the issuance of a certificate of incompetence, usually by the admitting physician. Although the children living in institutions suffer the permanent condition of severe to profound intellectual impairment, it is interesting that once they reach the age of majority they are deemed competent unless declared incompetent by a court action. Second, in the proposed legislation there is a clause which states that after discharge from an institution, after a period of three months they will again be deemed competent. It sort of boggles our minds.

As a parent who has undergone having had a child who entered the facility at the age of 12, when I had very supportive staff and could look at my daughter's records and consult with them in relation to her medical care, her developmental care, etc, when she reached the age of majority it was such a shock, it was as if an iron curtain had come down. She had become an adult who was deemed competent. I had no access to her records. I could get verbal information but I could not delve any deeper.

As a result, we applied for committee ship and went through the court procedure of having her declared incompetent and my husband and I committees. That is insufficient legislation in that it only sets out guidelines in handling her estate; she has no estate. Then it simply says "committee of the person not defined." I welcome the guardianship legislation in that it does set out certain guidelines for guardians to follow in submitting an annual report. These are the things for which you are responsible. I think that is good and I welcome that.

The other thing I think would be an improvement, if we could apply for guardianship, is the access of information. Currently, having committee ship, I still have to apply under the Freedom of Information and Protection of Privacy Act to receive information. I only have to do that once, as long as I sign the right check box that says I want ongoing information. These guidelines for guardians should be more readily set out.

1350

We have some problems with it in that all the people living in institutions for the developmentally handicapped have been deemed incompetent. I may be misreading the proposed legislation, but it appears that, because they are incompetent, they will automatically have an advocate assigned to them. If I have statutory guardianship, which I

assume committee ship is, an advocate must visit every person in a facility to explain their rights to them and ask, "Are you happy with the representation you have by your guardian?" If that does not happen within that two-year period, then the public guardian becomes the guardian. The other thing is that, as I mentioned before, if the person is discharged from the facility, three months later statutory guardianship ceases. There is a void of how we are best going to protect the interests of people who are incompetent, who cannot give consent, who cannot give direction.

I am not saying for one minute that all families, all members, all parents are the best people to represent some of these people. Certainly there are instances where they are not, but there are also long-standing friends who may know the person very well and may have a substantial role in advocating for him and trying to provide him with the best quality of life.

We recognize the need for advocacy; we think it is a good role that should be played, but how effective this is going to be in a bureaucratic system I do not know. We have all had experiences with the public trustee. Certainly at the Rideau Regional Centre it took over a year for the public trustee to determine who was alive, who was dead and who was still residing in the facility before he got the personal needs allowances cheques sent out to the appropriate people. That is a long time in a person's life.

I do not want to take too long making the presentation, because I want you to have an opportunity to ask questions, so I think I will go through the highlights of the brief I have presented to you.

Again, Bill 74, it appears to us, is directed towards those who have difficulty in expressing themselves but who can give consent. It does not take into consideration the lifelong condition of profound and severe mental retardation. We recommend that this bill address ways in which people who are incompetent and who will always be so also be protected and served in a non-adversarial way.

We have a little problem with the term "advocacy" in that there are legal connotations which reflect confrontation. Some families are feeling threatened by this. If an advocate comes, is this somebody who is on the other side of a stream who is going to tell us that we are doing things wrong and has legal status which we as parents do not have? This is a little threatening, to the point that some parents are already applying for committee ship in anticipation of the passage of these bills.

Bill 108 appears to be directed towards those who are currently competent and to psychiatric patients who may have periods of competency. Again, it is the same basic issue.

Finally, Bill 110, which will be making amendments to the Developmental Services Act, does not take into recognition the lifelong condition of severe to profound mental retardation.

**Mr J. Wilson:** Thank you very much for your presentation. You did mention in your oral presentation towards the beginning, and I guess at the end, that you are worried that we might be setting up a somewhat adversarial system. Have you had experience at all with advocates, to this

point in your life, in your relationship with your association and your own family?

**Mrs Paproski:** Yes, I have, as a matter of fact. I can give you two examples. One was when we applied for committee ship and informed the institution we were doing so and why we were doing so. I wanted access to my daughter's records and to be more informed as to her condition and needs.

When we made the application, a request went to an adult protection services worker to go in to see my daughter, to inform her of her rights and to hire a lawyer on her behalf. Then eventually it got down to the public trustee, who put pressure on our application to change it to read that in the case of a disagreement with placement we would refer the matters to the court. The unfortunate advocacy role that was played there was that none of those people identified themselves to me, my husband or our lawyer. We were simply informed by the public trustee that there was a public interest group which was advocating for our daughter. I learned after I got the records there was an APS worker in Lanark.

The second example is a mother, who is a widow, who has a 26-year-old son living in the community who has been in group homes, in a family home program, in semi-independent living and then back into a group home. The latest question she was asked by the worker in the home was what her legal status was in relation to her son. I believe her son is 26. She feels this is coming maybe from the questions arising out of this proposed legislation.

**Mr Winninger:** I agree with much of what you have said, but there are a couple of points I would like to go over with you just so I am clear on them. The first one concerns the profoundly disabled. Are there not possibilities that profoundly disabled individuals might be able to indicate who they would like to be a decision-maker for them? Obviously they lack capacity, and a substitute decision-maker may have to be appointed. In that case, would not some of your clients be able to indicate a preference for one person or another?

**Mrs Paproski:** They may, but whether they would be choosing wisely might be a question. It may be the person who takes them out for ice cream cones; it may not be the person who supervises their diet. If one is looking at the long-term results of that decision, I would question whether it is really in their best interest and whether they have the competency to understand how it is going to affect them in the long term.

**Mr Winninger:** I suppose that is also a matter for the judge hearing the application for guardianship to decide whether this person's choice is an appropriate one or not.

**Ms Allingham:** Many times we find that our people give the answer they expect the person asking the question wants to hear. They have learned it as a defence mechanism, and we are concerned about this.

**Mr Winninger:** I see. I just wanted you to know that no one is ruling out a wish of a profoundly disabled individual to indicate a preference, subject to the kinds of safeguards that come into play, when a court has to determine guardianship. I also wanted to find out if you were

aware of some of the transitional provisions in Bill 110. You asked, if you are appointed a committee under the Mental Incompetency Act, whether this would trigger an advocate with the implementation of our new legislation. If you are a private committee and you have been judicially appointed and you file that committee ship within two years of the act coming into force, then you become that person's substitute decision-maker or that person's guardian under the new legislation. There is no requirement for advocacy in that situation under the legislation.

**Mrs Paproski:** But you have to refile within two years. Is that the situation? So even though I have committee ship, I would have to refile?

**Mr Winninger:** Just to become official under the new legislation as a substitute decision-maker guardian. But if, for example, there is no private committee and the public trustee was the committee for that individual under the existing legislation, then if the new public guardian and trustee is to continue in that role and the person objects, a guardian may be called. That is in regard to the public trustee's role and not in regard to your own role as a private, judicially appointed committee.

1400

**Mrs Paproski:** You see, the majority of the people in institutions come under the public trustee. There are very few people who have committee ship, primarily because there has been a policy to involve families and to discuss things with families. People have not wanted to go through the court process. It can be lengthy, it can be expensive, it can be beyond some people's means. If this goes through, then the majority of people will come under the responsibility of the public trustee and the public guardian, which begs the question what parents and families should do, because they are not accorded any direction in this proposed legislation.

**Mr Winninger:** Legislative counsel can always correct me if I am wrong, but in this particular situation there is no dramatic change from the existing regime in the proposed regime, only in so far as before the new public guardian and trustee takes over existing files there is an opportunity for the vulnerable adult, if you will, to object and have an advocate called. Mr Fram may be able to amplify on this.

**Mrs Paproski:** What if they cannot object? I am looking at people who function at a two- and three-year-old level, who are non-verbal and cannot object. They have no idea what you are talking about.

**Mr Fram:** The first thing you raised was the problem you now face under existing law when your child becomes 18 years old or there is a discharge from an institution and the public trustee no longer manages the flow of funds. Under this legislation there would not be a problem because unless the person objects to the continued management when an advocate comes out, the public trustee would continue to manage the property to whatever age. If the family members wanted to take over the management from the public trustee, all they would have to do is apply and then they could take over the management.

Many of the kinds of situations that call for decision-making would be physical care decisions. Under existing law if a person is getting medical care in a facility, the family has no right to consent to or refuse treatment in those situations. Under the Consent to Treatment Act the family would have the right to make those decisions that the person is not capable of making. I think that basically covers most of the concerns.

Going further, under existing law if the family wants to gain committee ship of the person without guidance, there is necessarily a hearing before a judge. Under the provisions for guardianship, where the person who is going to have a guardian does not object, there is no requirement for a hearing. The documents addressing incapacity are filed along with the plan of where the person is going to stay and what kind of care he or she is going to get. It is called a guardianship plan, and if there is no objection by anyone, then the parent, brother, sister or other friend or family member can get guardianship.

**Mrs Paproski:** They can apply? This is what I found not very clear in reading the proposed legislation, especially if it was somebody residing in an institution. The onus is on the family member or the long-standing relationship to make application?

**Mr Fram:** Right.

**Mrs Paproski:** To whom do they make application?

**Mr Fram:** They would apply to the court, but through the public guardian and trustee's office. The requirement should be simple enough that it could be done by people by themselves, unless there is someone who objects to it. At the point at which there is an objection, a struggle, like the Justin Clark case, then you are into the usual kind of court procedures, but otherwise it should be a fairly straightforward procedure.

**Mr Delsnyder:** That is the current legislation as well, is it not? The procedure is to go through the public trustee?

**Mr Fram:** It does go for review now to the public trustee.

**Ms Carter:** I am a little concerned about your view of the advocate. It does not quite correspond to my own impression of what the advocate would be and do. First, this is somebody who is going to find out the opinions of somebody who by definition is isolated, does not have family or friends looking after him in an adequate way; otherwise the question would never arise. They are not going to intrude into a family situation unless there is good reason, and sometimes there might be good reason.

In the case of people who are profoundly disabled, as are the ones you deal with, I cannot see in what circumstances they would have an ongoing relationship with an advocate if by definition they cannot really express any wishes of their own. I see an advocate as somebody who would only be called in if there was some reason to think there were problems. Then their response would be to follow up some of the other possibilities that we have been looking at, such as guardianship, if that was seen as necessary.

As an example, if you have a relative who is in care in an institution maybe some distance from where you live

and you cannot supervise how they are being cared for, the advocates who already exist in psychiatric hospitals, for example, have sometimes been able to alert families to problems they would otherwise have been unaware of. Then the families have been able to act on the basis of that information and have in fact been very grateful for it.

**Mrs Paproski:** Now we are talking about different types of advocates, because there are obviously advocates who exist and advocate on behalf of people. But this Advocacy Act is setting up a more formalized process of advocacy. It was my understanding in reading the proposal that the officially appointed advocate is going to have to review all those in institutions to see if they are happy with the advocate they have. They have a two-year process in which to do this. I am just wondering how cumbersome or expensive this may be and whether it is possible.

**Ms Carter:** I do not recollect anything of that kind in the act, actually. If you could point that out to me I would be interested.

**Mrs Paproski:** I have the quote here someplace.

**Ms Carter:** I do not think there is a provision of that nature.

**Mrs Paproski:** You have clarified a number of points that we certainly have had concern about. As I say, basically the whole thing seems to be so geared to people being able to give consent that this very small population, but most vulnerable population, did not seem to have their issues addressed as to how they were going to be protected.

**The Chair:** I think Ms Spinks has some clarification here.

**Ms Carter:** Would counsel like to comment briefly?

**Ms Spinks:** Yes, I just wanted to clarify that there is no provision in the Advocacy Act of the type you describe which would suggest that an advocate would take it upon himself or herself just to continually review the actions, for example, of a guardian or in an institution. There is a role for advocates in terms of assessing the types of policies and practices of institutions, but they would not be intervening in individual cases unless there was a specific request by the individual or a referral by a third party, which would be followed up with the individual. In your case, if there is an inability there to give any meaningful direction to the advocate there would be no involvement.

**The Chair:** Ms Allingham, Mrs Paproski and Mr Delsnyder, I would like to thank you on behalf of the committee for taking time out and giving your presentation.

1410

JOHN PROPPER

**The Chair:** I would like to call forward our next presenter, John Propper. Would you please introduce yourself for the record and then proceed?

**Mr Propper:** My name is John Propper. Thank you very much for the opportunity. My sister, whom I shall call Anne, a fictitious name, is now in her late 40s and has been schizophrenic for over 20 years. I would like to put

on record that if Anne were to find out that I was in fact making this presentation she would be very upset. I ask members of the press who are hearing this or reading about this to not report on it.

Let me say a few things about the effect of Anne's illness on her life and on those around her. I will start by describing what Anne is like when she is not under medication, and she is not under medication now.

The first time Anne was involuntarily committed, over 20 years ago, we had a psychiatrist visit at the house. He was sitting in the living room when Anne walked in. All she did was walk in and walk out again. I do not even think she said a word. The doctor turned to me and said, "How long has she been like that?" It was that obvious that Anne needed help. Of course, the doctor did talk to her at length before he authorized the involuntary commitment, and another doctor was involved as well, so it was a very rigorous procedure that was followed.

Since then, Anne has been found, variously, curled someplace in the foetal position, incontinent, actually unable to walk and who knows what else over the last 20-odd years. I have personally arranged two involuntary commitments, and I know of at least one other. These events, as you know, include the use of force, police, ambulance attendants, distraught family members, neighbours and friends who happen to be around—all in all, a pretty traumatic experience for everybody involved and mostly so for the person being committed.

What is Anne like when she is well?

Prior to her illness, Anne was an honours student at the University of Toronto, an English major. A byproduct of her illness was interrupted studies—she still has not graduated. During the past 20 years, Anne has had normal relations with family and friends for only a very few years and only while on medication. Prior to the onset of schizophrenia, Anne was an honours student and academically gifted. During the few and short periods when her illness was controlled with medication, Anne functioned well. The family enjoyed her warm company, she was fully employed and started working towards her degree again. She met a man and got married. She was just like an ordinary person, and a far cry from the Anne I described without medication.

Anne's history, I am sure, is not unfamiliar to you: Schizophrenic, but responds well to medication; stops taking medication and becomes too ill to realize she needs treatment; a downward spiral ending with involuntary confinement, and then we start all over again.

As I mentioned, Anne has been involuntarily committed at least three times, and each time this unpleasant process was her only road back. After medication took effect, she was grateful to be back with family and society. Although I am sure she was not happy to have been involuntarily committed, I never felt her resentment of this. The important point is that no matter how unpleasant the process, after my sister had stabilized, she was grateful for what had been done for her. Being healthy was worth it.

Unfortunately, after some time Anne would typically become convinced that the medication was unnecessary, go off drugs and suffer a relapse.

As I mentioned, she met and married during 1983. Shortly afterwards, she stopped taking her medication. The inevitable happened. Anne became ill again, left her husband, disconnected from family and friends and quite literally just wandered around the streets, just like the people you see downtown or on TV. As with past relapses, she invariably lost all her possessions, job, money, clothes and so on.

The family desperately tracked her wanderings and tried to have her committed. We found that the laws had changed dramatically since we had last hospitalized her some time in the early 1980s. A police officer told me once that suicide attempts with slashed wrists were being discharged. His quote was, "Good luck on helping your sister."

The medical profession fears legal problems, probably for good reason. Anne, for example, is very clever and would be knowledgeable of the law. She would be explicitly threatening, I am sure, to doctors. The police, doctors and other well-meaning professionals seem to be helpless in the face of current laws.

At least once since 1983 Anne has been hospitalized. The family was notified in late 1987 that Anne had been admitted to North York General Hospital's psychiatric ward. She was found incontinent and unable to walk. That is all we know. She accepted visits from some of the family. Anne stayed in the hospital for about a month and then left. I urged the hospital to keep her until the medication took full effect. They said she had improved significantly since she had been admitted. Nevertheless, because of the law, the hospital could not guarantee that Anne would stay long enough for the medication to take hold. Obviously, Anne did not stay.

Since 1983, contact has been infrequently maintained through an old friend of the family. Anne would meet this woman now and then, and as long as the conversation did not drift to Anne's condition, this family friend was able to maintain pretty good relations. Except for emergencies, this was the family's only knowledge of Anne up to the last year or so. More recently, the family does have intermittent contact carefully arranged through this friend. Mine is limited to infrequent and incoherent, pretty much unreadable letters, and my mother's contact is infrequent and tense meetings downtown, typically. Anne is unemployed and living downtown in a rooming house someplace, presumably on welfare.

We have only very sketchy information about how Anne has lived since she went off medication in 1983. Although Anne is now obviously able to walk and is not incontinent, I am not satisfied that she is well. Clearly, she is not living her life to its potential. Clearly, neither Anne nor society's best interests are served by her twilight state.

I fail to see how Anne's freedom to not take the medication is to her or anyone's advantage. I fail to see how a law which allows someone to live half vegetated when effective remedies are available is in the interests of anyone. Are Anne's or society's interests really being served by existing and proposed laws?

If the issues are personal freedom and individual rights, then the questions should be, freedom from what? Rights to do what? Laws often restrict freedoms and limit rights. I

have to wear my seat belt, a motorcycle helmet and not drive through red lights. Obviously I cannot do as I wish all the time. If these kinds of laws make sense, then so do laws that allow schizophrenics to lead normal lives.

One suggestion I have is to include, for example, a special provision in the laws to ease requirements for involuntary treatment if a person has a known history of mental illness and his history indicates that the person responds well to medication.

Another issue that needs somehow to be dealt with is the disincentive for doctors to decide objectively. If doctors believe that a person should be committed, they know they may wind up spending expensive time defending their actions. Far easier to not act at all. Somehow the system has to provide an incentive for fair judgement by professionals.

**Mr Poirier:** Any specific points in the bills that concern you pertaining to schizophrenics? What would you like to see removed or added or changed, specifically?

**Mr Propper:** I guess the last point. If the subject has a known history of mental illness and also has a history of responding well to medication, I think in those circumstances the requirements for involuntary commitment should be less strict than otherwise.

**Mr Poirier:** Who would decide that?

**Mr Propper:** I do not feel qualified to judge that. Obviously, doctors. I am not sure what I have to choose from.

**Mr Poirier:** How about the role of family in that?

**Mr Propper:** In deciding?

**Mr Poirier:** In deciding or in the entire issue, the whole issue of schizophrenics. How about family? What do you have to say about that?

**Mr Propper:** I would say that the family is an important part of it. The family knows the patient and presumably has an interest in the wellbeing of the patient, and I do believe the family should be involved in the decision. I cannot say I have really thought through what the mechanism by which that would occur would be, but it makes sense to me now that you raise it, yes. Am I answering your question?

**Mr Poirier:** Am I asking the question well maybe, which is something else. But your being the family of Anne, how does it fit in? Are you satisfied that what was brought forward is going to help you?

**Mr Propper:** I do not feel completely knowledgeable to comment in a lot of detail on the provisions of the new laws at all. I know that since 1984 nothing seems to have worked, no matter how bad the shape she was in. My understanding is that, yes, in a very general sense the new legislation is going to make it even more difficult to act, and it is on the basis of that knowledge that I am here today.

**Mr Poirier:** Okay. So you are afraid the new legislation is going to make it more difficult.

**Mr Propper:** True. That is my understanding.

**Mr Sterling:** You are about the third or fourth witness who has given testimony about a close family member. I

think you would be interested in the exchange we had yesterday afternoon when another witness outlining the same problems with a close family member brought it to the attention of the committee.

Basically, it is my belief that while Bill 74 very much works against the good of schizophrenic patients, I think Bill 108 probably assists in terms of getting guardianship and utilizing the powers of guardianship in order to get treatment for a brother or sister, as in your case. So perhaps you could ask the clerk to forward a copy of the Hansard from yesterday in terms of exchanges which went on to clarify those sections of Bill 108 which can assist.

**Mr Wessenger:** I would just like to concur with Mr Sterling that I think Bill 108 could assist in this regard, because from the way you describe your sister, she would be a person who would not be able to appreciate the reasonably foreseeable consequences of a decision or a lack of decision. I think that would be fair to say.

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**Mr Propper:** And thereby could be involuntarily committed?

**Mr Wessenger:** No. You could be appointed as a partial guardian. One of the interesting things of Bill 108 is it allows for the appointment of a partial guardian, and it seems in many of these cases the appointment of a guardian with respect to the matter of treatment alone would be an appropriate remedy, leaving the person with his other legal rights.

But in the area of treatment, I certainly think it would really give a lot more resources to try to deal with the situation of the chronic severe-schizophrenic patient. We had a situation yesterday, I think, that would have fallen under the partial guardianship position. So I am just suggesting that it would be of some assistance to you, and I think perhaps it might be of assistance also if we asked for an explanation of what the situation is now under existing law with respect to this situation.

**Ms Auksi:** The situation you describe is very familiar, and over the years a lot of concern has been expressed that the committal laws address the situation where someone is dangerous to himself or others but really do not address the issue if someone is mentally incapable and maybe quite, say, psychotic or dysfunctional. There is not a means for such an individual to be hospitalized, for example, if that is the only way he can be treated.

What the combination of the Consent to Treatment Act, Bill 109, and the Substitute Decisions Act, Bill 108, would achieve that could assist in those situations such as this is that if someone is mentally incapable and requires treatment that can only be provided in a hospital setting, a substitute decision-maker could admit him if he is not objecting. If he is objecting, then it would be necessary to obtain a court order for guardianship, which could be as limited as just for the sake of that hospitalization, in which case it will be necessary to demonstrate that he is mentally incapable of making that treatment decision and that, in fact, it is necessary for the hospitalization to occur.

The issue, then, is the treatment and not the public safety issue. A lot of people misunderstand the committal

laws as being somehow intended for treatment. As you probably know, if somebody is committed, there is still a separate issue of, does he consent to his own treatment? The purpose of the committal laws is different. Someone who is mentally competent can be committed; someone who is untreatable could be committed. The issue is the public safety issue of taking him out of harm's way, but on the treatment issue of someone who is mentally incapable to make his own treatment decisions, it is felt that it is better addressed through guardianship legislation which could provide the authority to hospitalize and treat if it is demonstrated that the person is mentally incapable of making his own decisions.

**Mr Propper:** So let me understand this. In brief, the new legislation would provide that it would be easier to involuntarily commit my sister or not?

**Ms Auksi:** You could characterize it as involuntary committal; it would amount to the same thing, in a way, because the person could, against his will, be hospitalized. In this case, the purpose would be explicitly for treatment and it would be on the basis of her mental incapacity. If you want to call it involuntary hospitalization, it is just that it has a history of meaning the other—

**Mr Propper:** What do we call it? What is the new phraseology, involuntary treatment or—

**Ms Auksi:** It would be admission to a hospital for treatment, and it could be for physical treatment as well, which of course is a big lack now. It could be for psychiatric treatment. The involuntary committal laws would still remain in the Mental Health Act for those public safety reasons. They are actually a separate issue from treatment, because treatment is a separate issue even when you get in hospital. These laws would deal with the issue of if you are incapable of making your own treatment decision, and if hospitalization is necessary for that treatment to happen, it can allow for that hospitalization to happen even if the person is objecting if he or she is shown to be incapable.

**Mr Propper:** And how easy is it for that to happen?

**Ms Auksi:** The provisions in the Substitute Decisions Act do allow for emergency guardianship orders, which can happen fairly quickly. For the ones who are not in that category, I would have to—Steve is here; he might be able to give more detail on that. I would not foresee these as being terribly difficult if it is fairly evident that the person is mentally incapable.

**Mr Propper:** Perhaps it would be easier, then, with the new legislation?

**Ms Auksi:** Absolutely. Certainly that was one of the intents. It was to address the issue of the person who is mentally incapable and may be very out of it, very dysfunctional, in serious difficulty, but may not actually happen to act out in a dangerous way.

**The Chair:** Mr Winner.

**Mr Winner:** I think the area I wanted to cover has been quite well dealt with. I would just say that I think this kind of legislation, a combination of Bills 108 and 109, can stop the revolving door syndrome you might have experienced, where your sister is involuntarily admitted to

hospital, given treatment, then released ultimately and goes off her medication. This would enable some form of guardianship that can persist as long as the court feels it is necessary that the guardianship be in place to ensure the treatment of your sister and to ensure it is not interrupted. I think quite a compelling case could be made on the basis of this legislation.

**Mr Propper:** And is the process of gaining guardianship lengthy, difficult or—

**Mr Winner:** As has already been stated, it requires notice and it would require the intervention of an advocate to advise your sister of her rights, but I doubt that it would take any longer, and I would submit probably a shorter time than is the present situation.

**Mr Sterling:** Could I just ask a question, interjecting and asking counsel?

**The Chair:** Yes, Mr Sterling.

**Mr Sterling:** You indicated that the provisions of the Mental Health Act remain there but the issue is different. If a person goes and obtains a guardianship order which includes the right to treatment and the right to forcibly take the patient to the facility—whatever power is needed in the order in order to do that—can the patient then somehow kick in the Mental Health Act after that, once the order has been made?

**Mr Fram:** Once the order has been made, it is not a mental health issue. It is a treatment issue dealt with under the guardianship board.

**Mr Sterling:** And the control over the guardian would be specified in the order?

**Mr Fram:** That would be specified in the order, plus there is the right to apply to end the guardianship or, where a problem with the order exists, to tell the public guardian and trustee to look in on the matter. But that is totally disconnected with the involuntary committal criteria under the Mental Health Act.

**Mr Sterling:** In terms of the exchange we had with this witness and the witness yesterday when we got into this specific issue, I do not know how Hansard is working on these committees, but sometimes they come quite a bit later. If we could get the Hansard from both of those, it might be helpful when other witnesses like this gentleman come before us so we could give them the benefit of the exchanges which have been undertaken in this committee.

**The Chair:** I understand Hansard is coming out fairly quickly now.

**Mr Sterling:** Oh, good.

**The Chair:** If Mr Propper so desires, I will make sure that the clerk does send him a copy of what happened yesterday, being as we did have a fairly lengthy discussion. Through our last presenter, we have spent almost an hour on this issue, so if you would like, I could instruct the clerk to send that to you.

**Mr Propper:** Thank you.

**The Chair:** On behalf of the committee I would like to thank you for taking the time out this afternoon and coming and giving us your presentation.

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# CANADIAN DIABETES ASSOCIATION, ONTARIO DIVISION

**The Chair:** I would like to call forward our next presenter from the Canadian Diabetes Association, Ontario division. Good afternoon. Could you please identify yourself for the record and then proceed.

**Mr Harvey:** Yes, my name is Peter Harvey. I am the chairperson of the social issues committee of the Canadian Diabetes Association, Ontario division. I am also a member of the national advocacy council for the Canadian Diabetes Association. We have prepared a small brief, and this brief is conditioned more or less on the fact that section 2 of the Advocacy Act is going to include people with diabetes, and that is predicated somewhat upon the phrasing of subsection 15(2), which refers directly to people with diabetes.

Because of the nature of the disease, which is set out in our brief, we do not necessarily see ourselves—I am myself speaking as a person with diabetes—covered within this act or the purview of the act from the point of view of the more contentious issues of having the requirement or need of an advocate in a situation where somebody is required to speak out for us. What we see within the act, which we like and support very much, are the broader concepts of education, the promotion of dignity, respect and so on for people who are disadvantaged, and it is to these issues that I wish to address my comments.

First of all, the Canadian Diabetes Association, Ontario division, is probably the pre-eminent organization speaking for the people with diabetes in this province. The aspect of this disease that is most distressing is the fact that in the next 10 years we are going to see the number of people with diabetes more than double. The statistics which are being reported by the Ministry of Health suggest that it is going to go from 5% or 6% of our population to well over 11%. Accordingly, it is going to be a very large body of people out there who are going to have to have perhaps access to some of the services which are indicated in the Advocacy Act, or the potential for those services.

The bottom line we see is really that education of the public is going to be a requirement if we are going to disabuse the public of the perception that people with diabetes are people with a disability—and it is a perception, because in all walks of life, people with diabetes now participate and carry on normal lives.

The advocacy part of the Canadian Diabetes Association has been instrumental in changing government policy with respect to licensing drivers. It has been instrumental in changing some of the attitudes. There are proceedings which have gone ahead and challenged the concepts of disability in the workplace and so on.

The proposed Advocacy Act has six stated purposes. Three seem to get lost in the expressed concern over the right to treatment, right to refuse treatment and so on, and these are the requirement that the Advocacy Act be looked at:

“(a) to contribute to the empowerment of vulnerable persons and to promote respect for their rights, freedoms,

autonomy and dignity; (b) to provide advocacy services to help vulnerable persons, (i) make their own decisions, exercise their rights, speak on their own behalf, engage in mutual aid and form organizations to advance their interests, and"—more important—"—(ii) bring about structural changes at the political, legal, social, economic and institutional levels... (f) to acknowledge, encourage and enhance individual, family and community support for the security and wellbeing of vulnerable persons."

We look at the question of "community support for the security and wellbeing" as being an all-encompassing form. It includes the right to share equally, I suppose, in our dollars for health care and so on and to ensure that people are receiving proper and adequate treatment.

In so far as the act itself is concerned, we have few complaints with it; we are very much in favour of it.

One of the problems we do see, though, is that the act is limited in so far as the application of advocacy services to people under 16 is concerned. If that means that we cannot go out and speak and create programs for the education of the public with respect to people under 16, then there is a deficiency there.

The second thing is that the act is limited to community programs. We feel that if the larger aspirations of this act are to be adhered to or given voice to, then it should be on a provincial basis, not just a community basis. Cost-effectiveness of delivery of programs is something that should be considered, and if we are dealing with a community-by-community basis, then it is not going to be necessarily economically effective. The concept of "community" we feel should be enlarged to include the community of persons with the particular disability or the group of people who are vulnerable, not just within a geographic community.

As I say, the Canadian Diabetes Association does support the creation of this act, it supports the roles which are being set out there and it sincerely hopes that it is going to be properly funded so that some of these educational programs on behalf of vulnerable persons can be launched.

**The Chair:** Thank you very much. Questions and comments?

**Mr Sterling:** What is it, section 15(2) of Bill 74? Is that the one?

**Mr Harvey:** Yes. Actually, it is paragraph 15(1)2.

**Mr Sterling:** Maybe you can help me out here, parliamentary assistant. Does that have to do with the groups that are to be considered to be on the commission or advisory board or—

**Ms Spinks:** The list of organizations refers to those that will participate in nominating people to the appointments advisory committee.

**Mr Sterling:** Did you want to be on that or not on that?

**Mr Harvey:** We would very dearly like to be on that committee as part of that proposal.

**Mr Sterling:** Sorry, it was just the clarification I needed. Thank you.

**Ms Carter:** I am very glad you like the act in general. We appreciate that endorsement.

I am interested in your recommendation 2 in respect to age. First of all, an advocate, by definition, is listening to the wishes of the person, and we have already had considerable discussion in this room as to what age a person is really capable of expressing his own best interests. I think that is a very difficult problem there, but it is my impression that the law, as it applies specifically to children, is actually stronger than the kinds of provisions we have here. For example, an advocate can request permission to enter premises, but if there is resistance, he or she has to retreat, as it were, and get a warrant. In any case, all they are going to do is to speak to the person and find out what his opinions are, and if the person does not want them there, then that is the end of it, whereas I believe the law as regards children is much stronger than that; they can actually be taken away from their parents and this kind of thing. I am just interested in what exactly you have in mind in this respect.

**Mr Harvey:** I guess, to comment on that, as I prefaced my remarks, the application of the individual advocacy role within this act is not seen as impacting a great deal on people with diabetes because of the nature of the disease. For most situations, unless there is another, secondary attribute there—

**Ms Carter:** Incompetent.

**Mr Harvey:** —incompetent, yes; I guess that is the word. When we look at sort of the loftier ideals of this act—to educate, to present community programs and so on—if it is to be restricted because of that section so that you cannot present programs for education and so on as it relates to children or specifically children's programs, then it is an unnecessary restriction.

**Ms Carter:** I do not see advocates as people who present programs.

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**Mr Harvey:** That is the issue, I suppose, where the act talks about programs within the community for advocates for the educational aspect, the question of creating programs for the—I go back to clause 13(1)(a) with respect to structural changes in the political, legal and economic spheres. Those are programs that seemingly are covered under this act and are being put aside with respect to the narrower issues. The CDA looks at it and says: "This act does allow a very broad advocacy role on behalf of all persons. If we are to develop community programs, then we can look perhaps to the commission for some funding for that."

**Ms Carter:** Yes, I understand that. But I wonder whether there might be other community provisions under which that would be provided. Counsel, do you have anything to say on that?

**Ms Spinks:** I cannot name them specifically but I think I should add that the age limit is really designed to refer to individual services, although I realize it does not expressly say that. I feel there is tremendous ancillary benefit through the public education role that the commission will provide to people, for example with diabetes in general.

There is a great spinoff from that that will benefit people with diabetes of all ages.

**Mr Harvey:** I suppose our suggestion is that the wording might be tidied up a little bit to make sure that these programs can run the complete gamut of people with diabetes or any other organization. I think, in my presentation, we did acknowledge that that is probably exactly what the age limitation is for.

**Ms Carter:** Thank you.

**The Vice-Chair:** Thank you very much for appearing before us today. I know you took time out of your busy schedule.

The next presenters are in the hall. They should be coming in momentarily. There has been one cancellation at 3:30 so the 4 o'clock person has been moved up to 3:30.

#### ADULT PROTECTIVE SERVICES ASSOCIATION OF ONTARIO

**The Vice-Chair:** Can I now call upon John Gearin and Maria Van Hoeve to present, please. I want to thank you both for coming. Please do not be nervous. Before you begin, can you please state your name for the record. Take your time and you can begin whenever you are ready.

**Mr Gearin:** My name is John Gearin and I am an adult protective service worker from Victoria county.

**Ms Van Hoeve:** My name is Maria Van Hoeve. I am an APSW, an adult protective service worker from Peterborough.

We are here on behalf of the Adult Protective Services Association of Ontario. That is our association. They have previously submitted a written submission and that is being handed out as well but you have probably seen it already. We are also here on behalf of our local group of APSWs in the Peterborough area, which includes Durham from the Scarborough-Pickering town line to Cobourg and north to the counties of Peterborough, Victoria and Haliburton.

**Mr Gearin:** The adult protective services program began in 1975 following the Hamilton guardianship project.

**Ms Van Hoeve:** Back then, a shift away from large institutions meant that more adults with developmental handicaps would be moved back to their communities. Due to the historical background of institutional care, communities did not have experience in long-term support or outreach services, and estimating the nature and number of supports required was difficult.

**Mr Gearin:** The Hamilton project suggested that the needs of these adults were largely social rather than legal and that it was more important to establish a service system to provide supervision and follow-up than to develop an elaborated system for legal guardianship.

**Ms Van Hoeve:** The APS program was designed to create this alternative by providing advocacy and case management to adults displaying developmental delays. Presently the need for advocacy on behalf of vulnerable adults arises in situations involving landlords, police, social workers, social agencies, the courts and other persons and professionals in the community. Advocacy is also required in the areas of housing, funding for adequate support in the

community, vocational support, volunteers, accessible transportation, access to legal representation and emergency shelter. Duties of an APSW also include short-term trusteeship, counselling, life skills instruction, doctor and dental coordination and public education.

**Mr Gearin:** APSWs advocate and encourage self-advocacy as well. APSWs have been involved with the Ontario Advocacy Coalition, the Fram report committee and the Coalition Against the Use of Cattle Prods.

**Ms Van Hoeve:** By the way, the colour is something we chose to liven up your day, so we will not be referring to section this and section that. It will be the cherry-coloured piece of paper and the purple piece of paper.

APSWs at their jobs listen to, validate, believe and support the individuals we serve and advocate on their behalf as if we were in their shoes. APSWs respect the individual's way as being right for them and avoid all advocacy delivered "in the person's best interests."

**Mr Gearin:** APSWs are located throughout Ontario, are 177 in number, and some carry case loads serving over 30 people.

**Ms Van Hoeve:** All APSWs are employed and supervised by local generic or specialized agencies such as associations for community living, which are funded 100% for this service by the Ministry of Community and Social Services.

**Mr Gearin:** Conflict-of-interest situations can arise when the APSW, with instruction from a client, advocates with vigour against an agency while that agency happens to be the sponsoring agency that employs the APSW. APSWs have recognized that conflict-of-interest situations with sponsoring agencies and MCSS are potential and real.

For example, a colleague of ours worked as an APSW within a municipal office where an APSW supervisor also supervised general welfare, family benefits, a recreation program, etc. A client of the APSW confided that she had been sexually assaulted by her landlord, who used his key to gain entry. The APSW immediately set the wheels in motion to respond. He contacted the local rape crisis centre to counsel the woman through her trauma, and he and centre personnel advised the woman of her legal rights. The woman was willing to take the matter to court. However, the APSW supervisor, upon hearing the APSW's plan, strictly forbade the APSW to pursue court action as the perpetrator was a successful and well-known businessman in the community. Any action the APSW took would have resulted in a harsh reprimand, as the APSW would be acting against his employer's wishes.

**Ms Van Hoeve:** In the tri-county area we serve, Lindsay, Haliburton and Peterborough, we are very lucky in that we have been sponsored by a private board. The board has been in place for approximately two and a half years and is responsible only for the tri-county area APSWs. They are not responsible or accountable to any other agency or service. Some APSWs are supervised by boards as well, but these boards usually supervise other programs such as family counselling, public health nurses, hospital staff, college staff, etc. These boards may not see APSW concerns as a priority and may be at a loss to explain

exactly what it is that an APSW does. In our area it is easy to see how independent sponsorship can alleviate all conflict of interest and make it possible for us as APSWs to advocate on behalf of our clients and not fear to be reprimanded.

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**Mr Gearin:** The APSAO initiated the direction several years ago to seek out a ministerial funding body that could supervise APSWs while not offering direct service, thereby creating no potential for conflict of interest. This was introduced to the Ontario cabinet in 1989 in the form of a brief, *Protection for Whom?*, presented by the Adult Protective Services Association of Ontario.

**Ms Van Hoeve:** We were wondering who would get the next paragraph with the word "vehemently" in it. I guess it is me.

*Protection for Whom?* vehemently suggested to the Ontario government that an independent advocacy system be set up. It suggested that guardianship and partial guardianship simply stripped persons of their rights and made them into helpless individuals who could not exercise their rights and did not have the right to have rights. APSAO also contended that APSWs were powerless to act with resolve for their clients without independence from the service ministry which pays their salaries. After initially placing APSWs in sponsoring agencies and proclaiming that APSWs provide advocacy and case management, the ministry seemed to become uncomfortable with this placement. In fact, the Ministry of Community and Social Services did not provide a mandate until six years after the forming of APSWs. It listed advocacy and case management as primary functions. The very next year the ministry issued a second, watered-down version of the guidelines which eliminated any mention of the APSWs' advocacy role. We feel that our example will indicate clearly to you that an independent advocacy system is essential.

**Mr Gearin:** The APSAO was established in 1980. The formulation of this association provides APSW members with a professional support system and a mechanism for systemic advocacy on behalf of the people we work for.

**Ms Van Hoeve:** With that said, we would like to present our critique of Bill 74 with relation to the APSAO submission. That is the white paper handed out.

**Mr Gearin:** Our association is very pleased with the introduction of this bill, as it upholds that all vulnerable people should and will have the opportunity to exercise their rights, not be subjected to abuse, have direct input into the direction of their own lives and to learn, as we all do, by the consequences of our actions and not by the well-intentioned wishes of others.

**Ms Van Hoeve:** We would now like to address the APSAO submission and elaborate on some of the points.

On point (b), no advocacy for children: In the process of developing an act involving advocacy for vulnerable people it is important to remember children. APSWs regard the ages between 16 and 21 to be the grey area. Persons in this area can easily slip between the cracks. Not only are children now becoming adults; they are now referred to

adult services, subjected to funding changes, programming changes and the advent of waiting lists.

We dealt with a situation where a 19-year-old ward of the children's aid society was under the threat of being discharged with no future supports in place. This person had previously become a crown ward at age 11 when she was declared vulnerable and at risk, and had since received 24-hour-a-day supervision and support. We feel that advocates can monitor such CAS cases to ensure that there is no time when a person receives no services and is just a number on a list.

**Mr Gearin:** Point (c), no provision allowing emergency entry to facilities, is another important point. Advocates must have a degree of power if they are to be effective. Not only is this power useful in ensuring that perpetrators will know they have to correct their behaviour when dealing with advocates, but it instils faith in vulnerable adults who may be seeking assistance as well. As APSWs we are called advocates. We must strive to do whatever we can on the instruction of our clients, yet we have no legal power to back us up. APSWs who are very good often bluff their way through many situations of advocacy, but the truth is that we as advocates need consequential power to influence change.

**Ms Van Hoeve:** Point (d) in the submission, no clause on non-instructed advocacy: Any true advocate will wish to investigate abuse if it is suspected. A clause to give them this recourse when they deem it absolutely necessary and appropriate is an essential tool. Vulnerable people include those who cannot make their wishes and needs known, and these persons must be guaranteed safety, security and wellbeing.

**Mr Gearin:** Point (f), no minimum number of regional offices: This point is especially important to advocates in rural areas. Rural areas are often the last to receive services and these services are few and far between. Also, community standards vary. The important issues in one rural area may not be applicable to another urban area, such as Haliburton and Toronto. Although present ministerial regional offices may be a blueprint for determining locations, all areas may not benefit.

The act must allow for more diversity and coverage. Emphasis should be placed on the number of possible requests in ratio to the number of advocates available. Fifty persons in need of advocacy may not seem like a lot unless the advocate's office is in Peterborough and the person lives two hours away in Highland Grove. A provision is required to allow for culturally sensitive and prompt responses to vulnerable adults who require advocates. Also, as people served may be transient, it is pertinent that there be an interprovincial transfer acceptance.

**Ms Van Hoeve:** Point (g), no duty placed upon government to respond: As we mentioned before, consequential power is essential in influencing change. The government must be committed to imposing its power in order to influence unacceptable situations that must be rectified. Lack of backup, response and interest by the government will undermine the advocate's work and will

lessen the faith people will have in the advocates and the commission.

**Mr Gearin:** Point (h), no promotion of community integration: The APSAO feels that the concept of integration should be stated in the act as a goal that must be reached as advocates perform their functions. We feel that community boards also have an obligation to stress and promote within the area served by them that access is a right and equality is a must. Advocates will reflect this philosophy when carrying out their daily duties. The APSAO currently recognizes media persons with an annual award to such journalists who promote integration in a manner that promotes dignity and understanding. In this way our association provides an example of how community integration can be brought to the consciousness of the community.

**Ms Van Hoeve:** Point (i), no duty to protect clients from abuse or neglect: Section 37 of the Child and Family Services Act sets out many examples of abusive situations that could be applicable to any one of us. Bill 74 should state that advocates have a duty to protect vulnerable adults and perhaps incorporate some of the wording of this section to set out the boundaries of response.

**Mr Gearin:** Point (j), inadequate protection for most vulnerable citizens: In addition to our September 1991 submission we would like to emphasize communication. Advocates should ensure that all methods of communication available are utilized and every effort be made to attempt to empower individuals to communicate their wishes.

**Ms Van Hoeve:** Point (m), no provision for research: We feel again with this point that the onus should be on the board, with direction from people served by it, to initiate research projects. Advocates cannot be expected to investigate this area along with performing their many daily duties. Perhaps universities should be encouraged to promote research at a post-graduate level, possibly with the aid of Wintario grants.

**Mr Gearin:** Point (o), potential abandonment in coercive situations: Although a person may say they do not wish an advocate to be involved with them, there may be situational factors that leave the advocate unsure of the person's real feelings.

For example, a woman residing in a nursing home had recently requested that her APSW assist her in finding her a job in the community. The APSW found her a job and returned to inform the woman. The APSW was met by the woman and the administrator of the nursing home and was informed by the woman that she no longer wanted to work outside the home. The woman was visibly upset when the APSW was informed of the new decision. It appeared that she had been coerced by the administrator into changing her decision. Again, there is a line between intrusion and assistance. Advocates should have some options in cases where coercion is suspected and adults ask advocates not be involved with them.

**Ms Van Hoeve:** Here are some other points we came up with. Education and ongoing staff training: With regard to education and qualification for advocates, we feel that a comprehensive training package would include these sub-

jects: abuse recognition, reading environments and people; non-violent crisis prevention and intervention; philosophy; diplomacy; a course on bureaucracy—finding your way around and etiquette; bush-beating and mustering community links, and the proper steps in advocating.

**Mr Gearin:** Ongoing staff support to advocates should include scheduled and regular supervision, adequate resources, support and regular meetings with other advocates and a comprehensive health and medical package, which may include personal counselling costs and/or physical fitness costs in keeping with stress management and mental health concerns.

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**Ms Van Hoeve:** The vulnerable adult: Thought should be given to the ramifications of the situation of vulnerable adults. Often they will be living with or in direct contact with the person the advocate is questioning. The adult may be left with the aftermath of an advocate's visit to deal with. Although this cannot impede attempts to uphold a person's rights, it should be taken into account when handling cases. Perhaps advocate education could cover this subject.

**Mr Gearin:** Decisions and accountability: Serious decisions and subsequent interventions should be presented to the board and discussed in order to ensure accountability and responsible action.

**Ms Van Hoeve:** Situations: As APSWs, we are aware of some of the dehumanizing and degrading situations that some vulnerable adults are subjected to. Adults living in some group homes have their daily lives and activities dictated to them. They have their roommates picked for them and their clothes and their food also. They may even have their medication prescribed to them as dictated by staff needs. For example, the doctor and the staff and the adult come to the doctor's office. The doctor then asks the staff, not the adult, what the problem is. The staff might reply that the person is having trouble sleeping and then receive a prescription for sleeping pills. It is possible that the adult receiving the medication is never even consulted.

**Mr Gearin:** There are adults who are grounded as punishment in their own homes. People are put on time-out programs, locked in their rooms, deprived of any stimulation and prohibited from seeing their friends.

**Ms Van Hoeve:** Adults can be evicted from some government-sponsored homes within 24 hours and continually hear the threat from staff and administrators as a way to modify their behaviour and make them compliant to home policy.

**Mr Gearin:** Adults are yelled at by support staff in what is supposed to be their own homes—not that any service provider should have the right to yell at anyone, regardless of where it is.

**Ms Van Hoeve:** We are aware of a man who was sexually assaulting three women on a regular basis. The women and the man had all been labelled. When questioned, police said the man would not be charged because he probably was not competent. The three women's statements

were not taken seriously because, "You people don't make good witnesses, you know."

**Mr Gearin:** We know of situations where siblings have unjustly attempted to have other siblings declared incompetent in order to maintain power over their inheritance.

**Ms Van Hoeve:** We know of cases where landlords have people sign leases that fall far outside the limits set out in the Landlord and Tenant Act for financial gain and control of the persons' living situation.

**Mr Gearin:** Adults are being denied generic services that are funded for all people by the province, for example, family counselling, men's violence groups, women's crisis shelters, all because of the label society has placed on them.

**Ms Van Hoeve:** We believe that examples such as these are proof that Ontario needs an independent advocacy system as suggested by Bill 74.

**Mr Gearin:** It is time to serve more than the squeaky wheels out there. Silent voices need the floor.

**Ms Van Hoeve:** People need a voice that will not back down, that has community backing and the law, if needed, on their side. The government needs to properly and promptly support this voice.

**Mr Gearin:** It is going to take all three political parties working together to right the wrongs that people we serve suffer daily.

**Ms Van Hoeve:** Rose Anne Davis is an APSW and colleague of ours from London. She made us promise to say we are damned good at what we do. We feel we are, and with this act up and running we can provide an even better service.

**Mr Poirier:** The principle is okay. Do you see any points in particular in the act that could be improved? Did you really take apart the act to find out the principle of the act and how it would help you or hinder you to do what you do in your everyday life? Have you found anything?

**Mr Gearin:** Yes, I guess basically the purpose of the act and why it was set up in the first place, the fact that vulnerable adults are being identified and that this act places recognition on the needs those vulnerable adults have.

**Mr Poirier:** But are there specific points in the act as it is written down? Did you get a chance to take a copy of the act and really try to translate that, point by point, into everyday working conditions for you as advocates?

**Mr Gearin:** Not at great length. I have skimmed through it a couple of times, not in the detail that I would like.

**Mr Poirier:** We are seeing a lot of people coming forward and just about everybody supports the principle, but they are finding out that when they study the act, between the principle and putting that into practice within a legal framework it is a whole different story. That is why I want to know. You might want to go back and have a very close look at the act to see what that means legally for you. According to what we hear in a lot of other places, it may not be what you think you are going to see with it. I just

wanted to tell you that, because you told me you did not really go into detail. May we invite you to do so, and if you have some further comments make sure you bring them back to the committee. Thank you.

**Mr Curling:** I can see that you have lived the life of an advocate and you have shared your experience with us. I just want to share with you certain things too that all three parties, all three governments, have faced.

Early in your presentation you said the shift away from large institutions meant that more adults with developmental handicaps could move back to their communities. While in principle that is all very well, in the community where there is love and support that would be there and they can easily mix back with the community, maybe get that kind of help, what they have found is that when they have psychiatric patients in institutions and put them out of institutions the support system really was not there.

**Mr Gearin:** I do not mean to interrupt, but we do not deal with psychiatric patients.

**Mr Curling:** No, I am just using an example to say what is needed when you put people back into the communities. As I said and as my colleague was trying to say, we find that the principle is solid. If any government decides to send out the signal that this is the way to go, without giving the proper—I think in the last part of your presentation you mentioned that support must be there. "Support" means adequate financial support. Then you actually articulate in detail the things that are needed for the advocate to do the job well, meaning we must have money in order to do that.

With reality hitting home these days, in other words, that there is just so much money to go around, do you feel that the government should make a pilot project first and see how it works or say, "We'll have advocates representing all types of people who need it badly, we know," and maybe come to a crash because they do not have the sufficient funds? Would you support the direction of going as a pilot project, or should they go ahead full blast and institute this advocate program?

**Ms Van Hoeve:** I think that at the moment the adult protective services program is sort of a pilot project in itself, in that we advocate on behalf of our clients, and it seems to work. We advocate in the community for supports for people we support. That is the hard part, finding the supports in the community, but as an advocate that is what we try to do in our community. I think we already do it and it does work.

**Mr Curling:** You are saying now that the pilot project is you and that is sufficient, that the governments have done their pilot projects and that we must go right ahead and fund this to its fullest cost?

**Ms Van Hoeve:** We were never set up as a pilot project but I think we serve as a good example of something that is a good idea and does work.

**Mr Gearin:** The model we use could be implemented to serve vulnerable adults across the province by patterning it against the APS setup right now.

**Mr Sterling:** You say in your brief that you support the right of an advocate to enter a facility. Subsection 19(1) of Bill 74 says "where there are or may be vulnerable persons, without a warrant and at any time that is reasonable in the circumstances." Do you believe that advocates should have greater powers than the police?

**Mr Gearin:** Personally, no.

**Mr Sterling:** Okay.

1510

**Ms Carter:** First of all I would like to welcome you both here, particularly since you have come from my neck of the woods. I have already spoken to Maria in my office. I want to congratulate you on doing a wonderful job. You are the experts on this issue. I think you are the people who know almost more than anybody what the problems are out there and how we need to deal with them. I want to thank you for some very good specific suggestions you have made in your brief. I think you have really given us the chapter and verse of why we need an Advocacy Act and filled in some of the gaps we may have had.

I have just one question for you. Your job comes in two parts: You do case management work and you do the actual advocacy of listening to people's wants. You say that you want to come under the Advocacy Commission when this goes through, that you want to become advocates. It seems to me that there is some balance in the job as you now do it. We had a witness this morning who was also a PSW, and she said that doing the case work helped her to achieve credibility with the people for whom she was advocating. I am just wondering what would happen, if in fact you did go under the Advocacy Commission, to the other part of your work, to the case work management?

**Ms Van Hoeve:** The association's stand is that we feel advocacy and case management cannot really be separated; they happen at the same time. A person comes into your office needing emergency housing. Case management says, "We will look at this, this and this," and sends them in the proper direction. Unfortunately there is a waiting list 50 people long for that same service. That is where the advocacy comes in, doing whatever is possible to get that person the services he needs. I think that could possibly apply under the Advocacy Commission. It is just part and parcel, we feel, of the same job.

**Ms Carter:** So you do not see case management as going beyond what is laid down in this act? As I understand it, it is listening to people, finding out what their wishes are and communicating those in the right quarters. You would see advocacy in general as sharing this responsibility for some case work?

**Ms Van Hoeve:** I think that in the process of getting to know someone and his needs, advocacy and case management do happen at the same time unless he has someone else who can advocate. Then, once the service was in place, the case manager could take over and manage that.

**Mr Gearin:** Could I add one comment? I appreciate the fact that you identified us as experts in this field. We are not. We are the front-line staff who face the walls day in and day out. The people who help our association, and

who assisted us with writing the submission we gave you in September, are the experts. The other experts out there who will be able to tell you how this action directly affects them are the people this act was created for.

**Mr Malkowski:** Do you think all APS workers should be moved under the Advocacy Commission?

**Mr Gearin:** One more time please? Do all advocates—

**Mr Malkowski:** Do all APS workers agree that their jobs should be transferred to be under the Advocacy Commission?

**Mr Gearin:** No, but the majority do. For the past three years we have discussed it at our annual general meeting and asked, by a show of hands, who felt we would benefit under an independent governing body other than MCSS, which has potential for conflict of interest. Not all APSWs agree but the majority agree that the program should be transferred.

**Mr Malkowski:** You would say the majority of APS workers agree it should be transferred to under the commission.

**Mr Gearin:** Yes.

**Mr Sterling:** Just as a clarification, in terms of the case load you undertake, how does the client get to one of your workers?

**Mr Gearin:** We have various ways: through hearing from friends who are also being served by our programs, police, social workers, the ministry being called. MPPs' offices call us on a regular basis, and the courts, crown attorneys, the jails sometimes.

**Mr Sterling:** You do not have any MPPs as clients, though, do you?

**Mr Gearin:** No comment.

**Interjection:** That is confidential.

**Mr Gearin:** That is confidential.

**Mr Sterling:** I asked the question because Rideau Regional Centre is not far out of the area I represent. I have always been concerned with clients who leave that institution but are lost once they get out of there. There is no tracking system as such when a resident of Rideau Regional is put out in the community. As I understand the law, the ministry loses its responsibility 90 days thereafter. After 90 days, if that individual gets lost, he gets lost.

**Mr Gearin:** I am not sure whether it is 90 days. At one point, when the government was looking at deinstitutionalization, there was an open-door policy in any facility for adult mentally handicapped adults. Anybody who expresses interest in walking out can walk out. The best the institution can do is try and hook the individual up with an APSW or another association for community living, but there is no onus. The responsibility leaves once they leave the doors, I believe.

Again, I guess we should have been a little clearer as well. Our program is entirely voluntary in that nobody is ordered or can be made to report to his local APSW office. We do see people we feel we might be able to serve, but the choice is theirs. I believe that in this province you are

competent until proven not. If you say you do not want service, you cannot be forced.

We are presently undertaking a survey to see if there is any way we can track some people, because recently some of our colleagues stumbled across a boarding house housing people who had left St Lawrence Regional Centre. Ten years after they had been discharged they still had the same clothes on as when they left. They were clearly marked—well, they were faded. These people were forcibly confined in their rooms. Their clothes reeked of urine. The operators of the home were collecting extra money from the government to pay for cigarettes for these people who apparently did not smoke.

**Mr Sterling:** My concern with the deinstitutionalization part is that in the last three governments it has been taken to a ridiculous end, and that is that the people who are left in Rideau Regional—I think there are 800 patients or residents—are not only mentally challenged but are challenged, many of them, with many physical disabilities. Putting them out in a community is not necessarily going to give them a better life in the end. They may not have as much freedom in the community as they do within Rideau Regional, which is quite a large residence, etc. My concern is that those people who want to argue that deinstitutionalization is the be-all and the end-all do not take the responsibility for going and tracking the 2,000-odd residents who have left that institution and asking them whether they are happy and whether they are living in the exact standards you have just outlined.

The parents of the people in that institution are very concerned because it cannot track some of the former residents. They have either died a short time after they have left the institution or they are somewhere and nobody knows where they are. There is a confidentiality-privacy issue, but there is also a caring issue in terms of society dealing with these people.

1520

**Mr Gearin:** One important fact you may want to keep in mind is that the incidents we hear about where people are not having a good go of it out of the institution—are you hearing about only the bad ones? Do you hear the success stories? I work with people who—one gentleman in particular whom I started working with six years ago is now part of the family. He was institutionalized at two, taken away from his parents and, because he was deaf and was not a prime candidate to be adopted, was placed in Smiths Falls. He is of normal intelligence. He was stuck in the institution, where his ability to learn and develop was severely impeded, for 25 years. He is out working on his own. Sure, he has his tough times, but with proper support he has come a long way.

**Mr Sterling:** I think the individual you are talking about is probably very high-functioning. But what has happened over time at Rideau Regional is that those people are all gone now and you are left with people who are very low-functioning. The concern is that if you close that kind of institution up without adequately providing in the community—some of them have to wear helmets around all the time so that they do not injure themselves. You are

getting down to people who need a phenomenal amount of care. It is questionable whether it is kinder of society to put those people out in the community and not keep track of them or to leave them in a residence which can care for them.

**The Chair:** Thank you, Mr Sterling. On behalf of the committee, I would like to thank you, Ms Van Hoeve and Mr Gearin, for coming and giving your presentation today.

**Mr Gearin:** Thanks very much.

DON WEITZ

**The Chair:** I would like to call forward our last presenter for the afternoon, Mr Weitz. Good afternoon. As soon as you are comfortable, please identify yourself for the record and then proceed.

**Mr Weitz:** My name is Don Weitz. I hope everybody has a copy of this brief and my letter to both Mr Cooper and Mr Morrow. I did not mean to leave out anybody else. I just thought I would put that since they are the Chair and Vice-Chair. Anyway, everybody is involved.

As I have said in my covering letter, I have included a copy of an article I wrote on very vulnerable children covered by the Child and Family Services Act, but as you will note, I hope that advocacy also extends to children, especially those who are locked up and often treated against their will, where consent is provided by the parents or guardian.

I have also included a short bibliography which lists some of the key sources or references in the medical and psychiatric literature regarding the brain-damaging effects of common psychiatric procedures, specifically electroshock, otherwise known as ECT or electroconvulsive therapy, and psychiatric drugs, particularly the neuroleptics, popularly called the major tranquilizers or anti-psychotics.

Thank you for allowing me the opportunity to come. I am representing myself, although I have been associated with various groups. As I said on the first page of the brief, I have been involved as a cofounder of a self-help group, which I understand still exists, called On Our Own, and cofounded the first anti-psychiatry magazine in Canada—I think it still is—titled Phoenix Rising.

I call myself a psychiatric survivor, not a consumer, a very misleading and unfortunate term for people who have survived abuses and mistreatment at the hands of health care professionals where there is very little or no choice. "Consumer" or "consumerism" implies choice. There is very little choice in the so-called "mental health"—quotes around that term—system in Ontario or anywhere else in Canada.

Where I am coming from is this. I want you to know where I am coming from, what my political perspective is, and I like to be upfront about it. I was locked up, against my will, some years ago during the Korean War. Fortunately I did not have to fight in that one, my parents arranged to have me committed against my will. I was, in the middle of the night, dragged from one end of the state of Massachusetts to the other, not knowing which hospital I was going to end up in. It was called the McLean Hospital, which is one of the most prestigious psychiatric teaching institutions in the United States and is affiliated with

Harvard University medical school and Massachusetts General. Anyway, to make a long story short, I was facing barred windows, a barred door, and within two months, I was subjected to the horrors of subcoma insulin shock treatment, which has never been officially banned in North America but has fallen into disuse. Anyway, I was never informed about the coma that I lapsed into. I was supposed to get subcoma, just before you go under. No one told me about the coma, which is a very common risk and which resulted in a number of deaths while people were being subjected to this so-called choice of treatment for schizophrenia. That is what I was diagnosed as, but my doctor never told that diagnosis to me. I had to find that out many years later by asking for a copy of my records, which took about four or five years to obtain.

I also want to mention very briefly the suicide of my dear cousin, Hope, whose father arranged for her to have a lobotomy and to have her committed—against her will, of course—in at least three or four psychiatric institutions, including the one I was in, but she was there at some other point. She had been on 20 different psychiatric drugs, had become addicted to at least two of them, and her health was directly threatened by several so-called safe psychiatric drugs. She was the black sheep of the family, too, if I may use that term.

I am coming here today to urge you to stay on the track of advocacy, to push hard for—that is not the only thing I am going to say about that—this act, which is not perfect, of course. But for far too long people in psychiatric institutions particularly, who are some of the most vulnerable people in our society, have not had the benefit of independent advocacy. They do not get independent advocacy now despite the fact that there is something called the psychiatric patient advocate office. It is not independent. All 12 advocates who work in the 10 psychiatric institutions work under a conflict of interest.

We warned the Ministry of Health in 1982 or 1983. I was consulted along with Carla McKague, probably the most outstanding advocate for psychiatric patients in Canada, who is with ARCH, Advocacy Resource Centre for the Handicapped. We told Ted Ball and David Corder, I think, at the time, “Guys, don’t set it up the way it’s going to because as long as you pay the advocates and make them accountable to both you and the patient there’s going to be a conflict of interest.” They did not listen to us. We also told them that the vast majority of the cases or issues coming to them would be legal issues, human rights issues. “No, no, no, you’re exaggerating,” is what we were told. Sure enough, the second and third reports of the psychiatric patient advocate office showed that 45% of the issues coming before the advocates were legal.

1530

I am very concerned, despite the fact that the advocates will be accountable to the Ministry of Citizenship, that there be strict independence, that there will be absolutely no scintilla, no shred of suspicion that these advocates are not independent and working for their clients as an advocate should, as all lawyers know.

Second, I want to stress the fact that in my opinion—and I think it is an informed opinion because I have been

on several committees and boards in my life—all commission members should be from the vulnerable groups. Not a simple majority; 100%. Why do I say that? Because if you want to give substance, meat, to the meaning of empowerment, that is how you can do it in concrete form. I am not talking about 61% or 51%.

I am sick and tired of hearing proposals that say, “Well, we’ll just get a simple majority,” and get on a commission. Say there were nine, and two of those nine are not from vulnerable groups but were mental health professionals or just health professionals. More often than not, health professionals dominate and manipulate on committees, in my experience, and I do not want to take that risk, certainly as long as I have something to say about it as a citizen. You get two professionals out of eight, nine or 10 and they will control the damn board. There goes your independence of thought, and there will be intimidation despite best intentions.

No, no. We have to have 100% on this commission from all the vulnerable groups—the hearing-impaired, vision-impaired, physical mobility-impaired, psychiatric survivors and the elderly—in my opinion some of the most disempowered groups, and people who call themselves child advocates.

I am a stickler for gender equality as well. I am convinced that if we had more women maybe some of the decisions would be a lot more humane. I have to tell you that I have been on a number of boards where a number of my other male colleagues who think they know what is best for women too are dead wrong and often communicate a lot of sexist stuff as well. Certainly in this day and age of equality I think it is time that we had no less than 50% of the people on any board of committee—in this case I am talking about the Advocacy Commission—being women. There also should be representation from the aboriginal people, first nations.

I want to talk a little bit about informed consent, something I was absolutely denied when I was locked up at McLean Hospital, which my cousin Hope was denied, and I have to tell you that in this great age in the province of Ontario there is virtually no such thing as informed consent in a psychiatric institution. I can back it up. You do not have to go and talk with psychiatrists. You just have to watch and talk with the people who have been the recipients of psychiatric treatment.

Psychiatric drugs are handed out like candy on the wards. Conservatively, 95% of people who end up in psychiatric facilities are subjected to psychiatric drugs. We are not talking about aspirin here. We are not talking even about Valium most of the time. We are talking about the heavyweights, mind-controlling drugs—I am not the first and I will not be the last to use that term—brain-damaging chemicals that are known to cause brain damage but which the psychiatric profession irresponsibly trivializes and denies. It is outrageous.

The Canadian Psychiatric Association: “Oh, no. It’s safe. It’s safe. It’s safe.” A new drug comes on the market with inadequate testing like clozapine, the so-called miracle anti-schizophrenia drug. Oh, boy, it only causes epileptic seizures in 5% of the cases, that is all. It causes a potentially fatal blood disorder in over 2% of the cases. The

drug manufacturers say it, National Health and Welfare says it, but I wonder what the psychiatrists are saying to their patients. There are about 80 of them on clozapine. This is only the newest of the neuroleptics for schizophrenia.

I am trying to get a copy of the consent form under the Freedom of Information and Protection of Privacy Act—I probably will never get that—that is specific to that drug. I want to know what the people are told. I will bet you they are not told. They are supposed to be told about epileptic seizures and agranulocytosis. But I want to see a copy of that consent form because what I am telling you is that people are being lied to under the name of medicine and science. I know what I am talking about. I have seen over 100 people on psychiatric drugs, conservatively—not just seen them; talked with them. I said: “Were you told about tardive dyskinesia when you were given Haldol or any of the other 20 neuroleptics?” “No. What’s that, Don?”

It has only been known for 20-some years that when you give somebody a chlorpromazine or Haldol or Mellaril or Stelazine, this is from the class called the phenothiazines, except for Haldol, but they are “neuroleptics,” and the term means nerve-seizing, a very appropriate term. Tardive dyskinesia occurs in up to 40% to 50% of people on any of one of the 20 neuroleptic drugs otherwise known as major tranquillizers, and it can start as early as six months after continuous drug use.

I have seen what the Clarke Institute of Psychiatry hands out and tells its patients about this. It is disgraceful; it is unethical. They do not say it is permanent. This is a permanent neurological disorder, iatrogenic, caused by the drug. But do you think the Clarke has the guts or intellectual honesty to tell that to its patients? No. They will cover it up because they want its patients to take the drugs so that they will be more manageable or controllable. That is the real hidden purpose of the drugs—quiet wards, guys, no problem, no trouble.

So when I read “consent to treatment,” I think of all the people who have never had consent. I think of my cousin. I think of my friend Mel at Queen Street. I think of a lot of other people who have had shock treatment who never knew that their brains would be scrambled and that they would have permanent memory loss, which occurs as a rule, that their brains would be for ever damaged, who were never told, because if they were honestly told that I am very sure they would not have consented.

Who is going to monitor these people? Who is going to monitor the doctors to ensure there is such a thing as informed consent? I agree that informed consent is finally spelled out in legislation, and whoever drafted that I congratulate, finally. It is also spelled out in the Child and Family Services Act but I still do not have faith that the psychiatrists are going to describe the procedure in detail, including the risks. So that is a problem for you. It is not just a problem for you; it is a problem for all of us.

How are you going to monitor that? How are you going to make sure that people have informed consent? By the way, I typed in that consent should be written and should not be implied. Please take out the word “implied.” It is too vague and subjective. It is unenforceable.

If someone is jerking his or her head like that, the doctor might say yes. The person is jerking his head because involuntarily he’s got a side-effect from a drug, which is interpreted as assent. That is very possible. I do not like implied things when it comes to consent. You should have it in writing. When you are talking about pills or electricity going through the brain—I am talking about 150 volts of electricity, because that is about the average amount given in the so-called modern or modified form of electroshock that is given at the Clarke and other places—people should damn well be very careful as to what they are signing.

1540

So, yes, I am very concerned, and yes, the treatments make the vulnerable even more vulnerable. That is the terrible irony and tragedy of this in psychiatry. I wish I had a dollar for everybody who told me: “Don, I am sorry I trusted my doctor, because when I came out I was worse.” I would be very rich. Almost everybody I talk with comes out worse after being treated by a psychiatrist or psychiatric staff of some kind. So I am very concerned about safe-guards; you are damn right I am.

**The Chair:** I was wondering if you would like to carry on or whether you would like to allow some time for questioning.

**Mr Weitz:** I would like to allow time, but I want to carry on, if I may, for three to five more minutes.

**The Chair:** Yes, you have a few more minutes; that is fine.

**Mr Weitz:** Thank you. I get very passionate about this.

**The Chair:** I realize that.

**Mr Weitz:** The issues demand it, and whether I am alone or not does not matter, because I am going to say these things. By the way, since I have said that certain procedures in psychiatry are very dangerous—I have in mind electroshock and neuroleptic drugs, and I should have added the anti-depressants, all of which cause brain damage—psychosurgery should never be given, never be prescribed to anybody who is “judged incapable.” Under the Mental Health Act, you can give psychosurgery to somebody who says, “Yes, oh sure, I’ll have it,” if the person is voluntary. I do not want to play games here. You cut it out completely, because it is as serious—it has been thoroughly discredited around the world, and it is a brain-mutilating procedure.

You would think we would have learned our lesson from the 1950s, but apparently not, because psychosurgery is still in the act. About 300 to 400 procedures are being done in the United States every year, and I understand that the Clarke has referred two or three people for psychosurgery in the last year. So it has not been totally abolished, in case some of you think it has.

Electroshock is on the increase in both Canada and the United States, and conservatively 1,500 to 2,000 people a year get it in Ontario. I cannot get accurate shock statistics because the Ministry of Health in Ontario does not keep accurate shock statistics. It is like trying to pull teeth. They are not published, by the way, nor is cause of death in

psychiatric facilities published. How do you like those beans? I have been after this for eight years. Publish cause of death in psychiatric facilities the way it is published in other health facilities. You cannot get the minister to move. It is an interesting omission in the stats.

Finally, everybody should be considered competent, capable. Presumption: why is it in section 8? It should be up front, under the word "capacity." Put it up front. That is a principle that this government is prepared to back: the presumption of competence.

The way it is, psychiatric staff need their heads turned a bit. I think they need quite a bit of education, because they do not presume or assume that we are competent when we go into admissions or emergency. They are all set to make all kinds of decisions for us. I think that is damn patronizing, it is unfair and it is irresponsible. You do not think incompetence or incapable just because a person is in need and because he or she looks funny or talks funny, or you cannot understand him or her because you did not bother to take the time to understand him or her. You assume competence. Of course, the word is "capable."

What words. They are such sweeping, all-inclusive terms. How dare I call you "incapable"? That is absurd. You can be capable of some things and incapable of other things. I know the act says it, but it needs to be emphasized: the principle of presumption of competence to make treatment decisions and so forth. That is what I wanted to say.

Finally, I want to add that I think it is time there was a bill of rights for vulnerable people in health care facilities. Nursing homes have a bill of rights, and I am glad they do, but I just wonder how enforceable it is. But for people in psychiatric institutions, institutions for the developmentally handicapped, group homes and so forth, there is no bill of rights. There is no bill of rights in law, and I want to see a bill of rights, if not in the Advocacy Act, then in a separate act, a bill of rights act for vulnerable people. I think it is time, and I want the government to put up stiff penalties for violations.

I included this draft bill of rights that I wrote, which I drafted based on one that was approved by the self-help group on our own back in 1982. It is not a lot to ask, but I think if we included a bill of rights that was enforceable and that had severe penalties—none of this \$5,000 stuff, \$20,000—you may then say: "Oh, that is quite a bit of my money. Gee, I could be sued for \$20,000." Right now, this is a joke. It is a slap on the wrist to say that someone who violates something gets fined up to \$5,000; that is maximum. It should be \$20,000 at least.

I think that is about all I am going to say, and I am going to leave time for questions.

**Mr Poirier:** Thank you, Don—if I may call you Don—for coming forward and doing this. I have looked as quickly as I could, because I was too intent on listening to you—I tried to listen with one ear and look with my eyes at least at your bill of rights for vulnerable people. Some points I have absolutely no problems with, right off the bat. But with your first point, "the right to remain free of confinement in any health care facility," I thought of schizophrenics for one, because we had a lot of testimonies

from family and friends and supporters of schizophrenics. Before you start to answer, because I know once you get going—

**Mr Weitz:** I am not answering.

**Mr Poirier:** Once you get going, we cannot stop you, but that is okay.

**Mr Weitz:** Some have been able to.

**Mr Poirier:** Further along in your other points for your bill of rights, Don, you are talking about "the right to choose our own doctor, therapist or counsellor while confined." The first point says "the right to remain free of confinement." Can you put that together for me?

**Mr Weitz:** Sure. That is a statement that people have a right to be free unless charged with a criminal offence. I could have spelled it out "and is charged under the Criminal Code with an offence." Everybody has the right to remain free. A lot of people have been locked up, as you know, because they may talk too loud or say weird things or embarrass their family, and without benefit of trial. Everyone has the right to remain free. That is fundamental in a democratic society unless you are charged with an offence and convicted.

**Mr Poirier:** Let me be the devil's advocate, if I may, okay? How about somebody who is perceived or known to be a threat to some other people's lives?

**Mr Weitz:** We have this Criminal Code, as you well know. The Criminal Code and civil code—not the civil code, but under the—

**Mr Poirier:** Common law?

**Mr Weitz:** Under the civil law, or common law, if I threaten you, you can use the law as it is to charge me with whatever, be it assault, be it libel or whatever. The law is in place. But do not use the places called psychiatric institutions for putting me away because I may be a nuisance or trouble to you or your friends or whatever.

**Mr Poirier:** But maybe you could be a threat without even threatening me.

**Mr Weitz:** How?

**Mr Poirier:** I guess I would find out too late, would I not?

**Mr Weitz:** You would have to spell that out. If you are advocating preventive detention, that was outlawed under the Canadian Bill of Rights, as you know, even before the charter.

**Mr J. Wilson:** That is right. Under John Diefenbaker, as I recall.

1550

**Mr Weitz:** Exactly, under Diefenbaker. That is one good thing I respected Diefenbaker for, but I do not have much respect for a lot of stuff in government. Do you know that in this society—and it is outrageous; think about it—preventive detention is alive and well in Canada and the United States in the form of involuntary commitment? Locking people up without trial or due process. That is justified in society—meaning we. Why? Under the guise and sham of mental illness, without a trial. That should be abolished. You should not be able to lock people up without

due process. Where are your principles? This government has condoned it. Every government, unfortunately, in North America, in Europe has condoned it: locking people up without trial.

Amnesty International still refuses to call involuntarily committed psychiatric survivors political prisoners. But when it happens in the Third World or when it happens in a poor country or in the Soviet Union, oh, sure, they are political prisoners. Not in Canada, where we do the same damn thing. Come on.

**Mr Poirier:** Okay. I want to be informed. That is why I am asking that question.

**Mr Weitz:** Well, that is what I am saying to you.

**Mr Poirier:** What if you have the state of mental health that would cause you to do harm to somebody else? How can you try that person? Would they be legally guilty of threat when it is the state of their mental health?

**Mr Weitz:** First of all, I do not buy the concept and the fiction of mental illness, which is logically absurd to begin with, because the mind is an abstraction, it cannot be diseased.

Second—and I could go further, but this is not a discussion of the pros and cons of the concept—you have no right to touch me or lock me up unless I have been charged, arrested and convicted. Unfortunately, we have legislation on the books in the form of the mental health act in every province and territory which allows just that. If I threaten you, then damn it, charge me, but do not play games with me, which is what the governments and authorities are doing now.

They are putting people in places called psychiatric hospitals which are even worse, in some respects, than prisons, and calling it treatment. It is not treatment; it is cruel and unusual punishment where you are intimidated. If you have ever spent time in a psych ward, you will know what I am talking about—or spent even a good amount of time working or observing. It is coercive, it has nothing to do with free choice. Your freedom is taken away, every hour or second of the day is virtually accounted for, the doors are locked and the treatment is prescribed for you without your informed consent. You cannot leave the institution when you want. Now, are you telling me that this is treatment or this should be helpful to someone who threatens?

**Mr Poirier:** Are you telling me that every person who is injured or killed or whatever first has to receive a threat from the person who is going to harm him?

**Mr Weitz:** You are not allowed to do anything unless the person has broken the law. Has he or she broken the law or not? It is very simple. It does not matter if he is hearing voices or not. A lot of us hear voices; even Gandhi heard voices. Of course, they locked him up too, not to mention Martin Luther King and some of the great leaders. It does not matter to me whether someone is telling me to go after someone; do I break the law or not?

This insanity defence should be scrapped too. The civil rights lawyers, I am sure, can be much more eloquent than I can about the justification for scrapping the insanity defence, which has resulted in a host of injustices.

**Mr Malkowski:** I have read a book called *Shrink Resistance: The Struggle Against Psychiatry in Canada*. I thought that was an excellent book and I recommend it for all MPPs to read. It is an excellent reference.

Are you aware that all the commissioners who will be nominated to the commission and the commission itself will be consumer-controlled?

**Mr Weitz:** Yes, I am, but a simple majority is not sufficient for me. It may be sufficient for you. Of course, I am glad it is going to be controlled by people who are still very vulnerable. But for the sake of empowerment, which is the first purpose in the act—empowerment with a capital E—51%, to me, is not good enough. It should be 100% if we really mean empowerment.

**Mr Winninger:** I think it is important that we not lose sight of some of the important points you have made today. I was particularly struck by your point about the conflict, perceptual or actual, that the psychiatric patient advocates experience right now, when they are being paid through the Ministry of Health and yet are advocating for patients who are in fact, in many cases, involuntary patients of the Ministry of Health. I think you made a very legitimate point there.

Second, I think you have made a very strong case for advocacy. You have described some of the negative side-effects, the iatrogenic effects—you used that word—of a lot of drugs that are administered, and certainly there is a very potent role for the patient advocate when advising a patient of his or her rights and he is being asked to consult a patient who may be receiving treatment on an involuntary basis.

Last, you did mention that there are many patients who may lack capacity for some functions but have capacity for others.

**Mr Weitz:** That is right.

**Mr Winninger:** Do you see a role under our Bill 108, the Substitute Decisions Act, for guardians who might be able to represent those patients and make decisions for those patients in some respects while in other respects deferring to the self-determination of the patient?

**Mr Weitz:** Yes. As long as the guardian takes the time and is committed to carrying out the expressed wishes of the person about whether he or she wants this particular treatment or not and so forth, as long as the guardian carries out what the person he or she is nominated to represent wants, I have no problem.

**The Chair:** Mr Weitz, on behalf of the committee I would like to thank you for taking the time out today and coming and giving us your presentation.

The committee adjourned at 1557.

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## Legislative Assembly of Ontario

First Intercession, 35th Parliament

## Official Report of Debates (Hansard)

Friday 14 February 1992

### Standing committee on administration of justice

Advocacy Act, 1991,  
and companion legislation

## Assemblée législative de l'Ontario

Première intersession, 35<sup>e</sup> législature

## Journal des débats (Hansard)

Le vendredi 14 février 1992

### Comité permanent de l'administration de la justice

Loi de 1991 sur l'intervention  
et les projets de loi  
qui l'accompagnent



Chair: Mike Cooper  
Clerk: Lisa Freedman

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# LEGISLATIVE ASSEMBLY OF ONTARIO

## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

Friday 14 February 1992

The committee met at 1012 in committee room 1.

### ADVOCACY ACT, 1991, AND COMPANION LEGISLATION

#### LOI DE 1991 SUR L'INTERVENTION ET LES PROJETS DE LOI QUI L'ACCOMPAGNENT

Resuming consideration of Bill 7, An Act to amend the Powers of Attorney Act; Bill 8, An Act respecting Natural Death; Bill 74, An Act respecting the Provision of Advocacy Services to Vulnerable Persons / *Projet de loi 74, Loi concernant la prestation de services d'intervenants en faveur des personnes vulnérables*; Bill 108, An Act to provide for the making of Decisions on behalf of Adults concerning the Management of their Property and concerning their Personal Care / *Projet de loi 108, Loi prévoyant la prise de décisions au nom d'adultes en ce qui concerne la gestion de leurs biens et le soin de leur personne*; Bill 109, An Act respecting Consent to Treatment / *Projet de loi 109, Loi concernant le consentement au traitement*; and Bill 110, An Act to amend certain Statutes of Ontario consequent upon the enactment of the Consent to Treatment Act, 1991 and the Substitute Decisions Act, 1991 / *Projet de loi 110, Loi modifiant certaines lois de l'Ontario par suite de l'adoption de la Loi de 1991 sur le consentement au traitement et de la Loi de 1991 sur la prise de décisions au nom d'autrui*.

**The Chair:** I call this meeting of the standing committee on administration of justice to order. I would like to advise the members that some of the people at the back of the room are having a little difficulty hearing, so when you are speaking could you please speak closer to the microphone rather than leaning back in your chairs?

#### ONTARIO SOCIETY OF PAEDIATRIC DENTISTS

**The Chair:** I would like to call forward our first presenters, from the Ontario Society of Paediatric Dentists. Good morning.

**Dr Maltz:** Good morning. Happy Valentine's Day, everybody.

**The Chair:** Thank you. Could you please identify yourself for the record and then proceed.

**Dr Maltz:** Sure. Can everybody hear me? Ladies, gentlemen and honourable members of the Ontario Legislature, I am Dr Jack Maltz, making this presentation as president on behalf of the Ontario Society of Paediatric Dentists. We have a special interest in Bill 109, since as paediatric dentists we are the specialists who provide comprehensive dental care for children, adolescents and special patients who have mental, physical and emotional problems.

We are all here today for one purpose only: to better serve the people, and specifically the children, of Ontario. The intent of Bill 109 may be to serve that purpose, but as

the bill is now drawn up it is very complex, confusing and not at all user-friendly. The bill is drawn up in such a way as to complicate needlessly what may be simple clinical procedures and it potentially gives too much power to young children before they are fully ready. The act is very ambiguous and creates potential problems where there do not seem to be any now.

The whole process of consent is redefined and is more complicated in many ways. Procedures to obtain consent under Bill 109 are onerous and burdensome, whereas until now they have been simple and straightforward. When Bill 109 comes into effect, if consent is given, it may not be valid or it may be refuted. Instead of assuming consent by the parent who brought the child into the dental office, a whole new inquiry process goes into place. If there are two parents, will I have to get consent from both? What if they are separated or divorced, and who has custody? Will I need proof of custody? If they disagree, will I have to call an advocate?

In my interpretation it takes away much of the power from the parents and assumes that parents will not act in the child's best interest. The bill may delay treatment and make treatment more complex, unnecessarily increase the cost of treatment and inflict needless pain and suffering on the children of Ontario. The management of difficult children will become more complicated and lead to potentially more painful procedures at a later date. The cost of health care, due to delays and complex treatments, will increase substantially for the government and for individuals involved. As a paediatric dentist I can foresee a whole new set of obstructions and legal manoeuvres that will not enhance dental treatment on behalf of the children of Ontario.

I would now like to go into specific sections of Bill 109 and follow certain interpretations, as I see them, to a logical conclusion. The crux of the problem is the judgement as to whether a child under 16 years of age is capable. According to my reading of subsection 8(2), anybody under the age of 16 is presumed to be incapable but the presumption may be rebutted, making the child capable for dental treatment. When a person becomes capable his own decision to give or refuse consent governs according to subsection 7(1). Thus, if a child refuses consent dental treatment may not be carried out.

Under subsection 10(7) if a child refuses to give consent for treatment on his own behalf, the dentist will have to start the difficult process of advising the child of his rights to meet with the advocate, and notify the advocate even over the parent's objections. The advocate may have to be called in even before the child is examined. Since many children may object to a fluoride treatment, dental injection or even cleaning of teeth, the advocate may have to be called in for trivial dental procedures that many children object to.

If the dentist judges a child under 16 years old to be incapable and wishes to carry out a procedure, the parent or family member may give consent according to paragraphs 1 to 8, subsection 16(1). However, it is not at all clear that the clinician can continue treatment according to section 17(b), where a family member or a parent cannot give consent if the incapable person might object to him making that decision, leaving the dentist in a quandary.

I would now like to go into some clinical applications of these interpretations and see how the law would impact on children refusing dental care in Ontario. A child is a growing individual and lack of proper treatment may lead to severe problems in the adult dentition that cannot be remedied at a later date. In a child under 16 years and medically compromised, who refused to consent to routine dental treatment, the situation may become more serious. The lack of timely dental care may affect the child's health and wellbeing.

The act does not envision children crying for relatively benign procedures, such as topical fluoride applications, cleaning of teeth, or the taking of pre-operative antibiotics. However, even these benign procedures, if not carried out, can lead to devastating consequences. A child who is a haemophiliac may refuse to take his topical fluoride application. This innocuous preventive measure, if not carried out, can lead to much more extensive treatment, hospitalization and even death. Many children strenuously object to these procedures, the consequence being that more painful and complicated procedures will have to be carried out at a later date if preventive procedures are not done in a timely fashion.

In a perfect world all things work perfectly. In reality, Bill 109 will unnecessarily delay treatment for a short period of time, and in some cases where there are appeals and delays, backlogs may reach unacceptable levels, especially if the system is clogged with trivial cases and unexpectedly heavy case loads, leading to shortage of staff and inadequate funds.

The cost of Bill 109 will be more expensive than the envisioned \$20 million to \$30 million if the number of consultations are more numerous than expected; and, as it is drawn up, I foresee it being used on a daily basis in all paediatric dental offices. What about lost operating time, lost hospital beds and operating room time? Who will reimburse the dentist for lost time and for consultation time with the advocate?

According to Bill 109, emergencies can be treated without the consent of the advocate. However, "emergency" is not adequately defined. Many dental emergencies are not life threatening or permanently disabling but, as many people can attest, very painful. Will we be able to do any work without consent?

In conclusion, Bill 109 was drawn up with excellent intentions. We have no problem with the intent of Bill 109. Nobody can object to the government appointing an advocate for the person who requires one. However, the way the bill is drawn up it will lead to unnecessary increase in suffering to the children of Ontario, and increase in cost to the parents, professionals and the taxpayers of Ontario.

I feel many of the pitfalls can be eliminated or tidied up by consultation with the professionals who are providing the care to the children of Ontario. Our group would be more than happy to do our part to help draw up a bill which would benefit everyone and protect the rights of the children and incapable adults.

1020

We recommend that Bill 109 be drawn up so that in regards to dental procedures:

(a) In the case of children under the age of 16, the responsibility should be accorded to parents, guardians, family members or public guardians and trustees;

(b) Children over the age of 16 should take on the responsibility themselves, or in conjunction with a parent, guardian or public guardian and trustee.

Thank you very much for taking time to listen to our concerns.

**The Chair:** Thank you very much. Questions and comments? Mr Wilson.

**Mr J. Wilson:** Thank you, doctor, for your presentation. I am just not familiar with what steps you must take now in your office to obtain consent. Can you go through that?

**Dr Maltz:** Yes, I would like to go through that, if you do not mind. If a child comes into my office, for consent I speak to the parent who brought the child in, and that usually is enough. Sometimes, in rare instances, with both parents working, somebody else brings the child in—an aunt, an uncle or even a neighbour. In cases like that, if there is an emergency treatment, I will notify the parent. Otherwise, I will proceed with an examination and then notify the parent.

**Mr J. Wilson:** Is there a legislated regime that you have to follow?

**Dr Maltz:** Yes. Right now we have to get consent from the parent.

**Mr J. Wilson:** From the parent.

**Dr Maltz:** Or a guardian.

**Mr J. Wilson:** Okay. Thank you.

**Mr Wessinger:** I would like to know how often in your practice you have children objecting to treatment.

**Dr Maltz:** You do not really want to know, do you?

**Mr Wessinger:** Yes, I would like to know. How often does it happen?

**Dr Maltz:** The thing is, we see children literally from newborns until the age of 18. I would really say two, three, four times a day. The thing you have to remember about children is that sometimes they yell and scream and carry on and they are not really scared; but this bill does not give me any leeway. The child may be just scared of new situations. If a child comes in yelling, screaming and crying and says, "Hey, I don't want to be here," according to my interpretation of this bill, I have to start putting a whole procedure into place, whereas right now, as long as the parent understands that the child is in—I speak to the parent: "Why is this child crying?" They may say, "He won't listen" or "He had an operation last week" or "Oh, he just

doesn't adapt well," in which case we deal with the situation differently. If a child had, should I say, reason for fear, we would try to calm his fears. If he says, "I don't like injections," we say, "Today we're not doing injections." That usually works. If it is a very young child who is just being stubborn, the thing is, we just go ahead and do the examination with the child sitting on the parent's lap.

**Mr Wessinger:** The next question I have is, with respect to the children, you feel they are unhappy being there. They are probably all unhappy being there; as adults, I do not think there is any difference. But do you have much problem with older children, say age 10 and up? Do you have much problem with them?

**Dr Maltz:** Yes, we do. The basic problem with young children is that their fear is unknown fear, it is a new situation fear, a new and a strange place. Older children are much wiser. They know what to fear. The thing is, they have much more specific concern: "I don't want that needle. I don't want you to use the drill."

The way we deal with it in my office is, we build up the child's confidence. If the child is scared of the needle, for example, he would come in and I would say: "Today we are going to be looking at your teeth. Today we are going to be doing dental X-rays," and he says, "No needle," and one of the things we do is reassure him, "No needle." But after two or three appointments, where he has built up enough trust in us, then we can usually go ahead and do a slight injection. Some children are paralysed by fear and they need additional help. We will use medication to calm them down or nitrous oxide or laughing gas to get them to relax, which takes away the pain of the injection so that after they have had one injection and see that it is not all that bad, most of the kids become excellent patients.

**Mr Wessinger:** Is there any age that children start, in your experience, treating the matter as adults?

**Dr Maltz:** I would say approximately the age of 12, somewhere in there. They really seem to understand what is happening and they can voice their fears and objections in a more concrete manner, whereas when a six-year-old comes in it is just a generalized fear.

**Mr Wessinger:** Thank you very much.

**Dr Maltz:** I have one other thing, if you do not mind. According to the bill, if you call an advocate, you cannot call him back for six months. That is perfect for dental recalls; we will be seeing them every six months.

**Ms Carter:** I think we do have to distinguish here between what you might call the kicking and screaming of a frightened kid and somebody, as you say, probably older than 12 who might begin to have a rational reason why they would not want treatment. I am just wondering how much these bills are going to change that situation. I think I would like counsel to comment on that, whether we are going to make that any more difficult for you under these bills.

**Ms Auksi:** I think we should say right away that the intent of the demonstrating a wish to make a treatment decision is that really you would be talking about someone who conceivably may have the capacity to make a treat-

ment decision for themselves as opposed to someone who is simply, as you are saying, expressing some generalized fear or anticipation of what may happen. I think it is recognized that if there is a need to clarify that in some way, it may be possible with drafting.

**Dr Maltz:** If I might comment about the advocate: I feel that would limit my power as a dentist—from a psychological point of view, not from a power point of view. What I mean to say is, if you are going in to have some surgery done, you have confidence that your surgeon is the best. You do not want somebody to come in and say: "I've got to tell him what to do here. Just wait a minute." Or, "Hey, wait. This is something that he doesn't know anything about. Let me just"—somebody else is coming in and interfering. Children understand the situation very well.

We have lots of children who come into our office who would not even open their mouths or would not walk in the door in a general office. They know when they are coming into our office that it is a special situation. They just seem to understand it. What will happen is they will understand what is happening, that we are there for their best interests, and they react totally differently. But if we have to get an advocate or somebody to come in, I feel that would take psychologically away from my power and would make it more difficult to deal with that child.

**Ms Carter:** It seems to me there are valid decisions to be made. For example, it took me a long time to realize that I would much rather not have a needle when I am having fillings; I would rather have the drill than have the frozen jaw. and I keep X-rays to a minimum and that kind of thing. So I think there are valid decisions there that one individual might make differently from another. Obviously it is hard to say at what age that begins.

**Dr Maltz:** Let's just take the haemophiliac child and expand on that. That sounds maybe innocuous where a 12-year old says, "I don't like the fluoride treatment and I'm not going to have it." The thing is, you would be surprised right now at how many kids do not like fluoride. It is worse than injections when we were kids. If this child does not get fluoride treatment he can get a lot of decay, and if he has a lot of decay, he will have to either be hospitalized or have the work done—by the way, haemophiliacs sometimes have the work done without any needles because of the danger of bleeding. So the child will actually suffer more. He may understand what is happening, but he may be paralysed by his fear.

**Ms Carter:** Thank you.

**Mr Sterling:** Could I just ask one question, perhaps of Mr Malkowski. Can we assure this practitioner that there are going to be advocates that are going to be available to his office every day and to every office similar to his? They are going to need an advocate every day, according to this legislation. Are we going to spend all our 150 advocates in the dentists' offices across this province? Can we assure him that the advocates are going to be there?

**Mr Malkowski:** I would like to refer this to Paul Wessinger, please, the parliamentary assistant to the Minister of Health.

**Mr Wessenger:** In my opinion, the obvious intent of the legislation is not to have an advocate called in for children who are incapable of making a decision with respect to the health matter. That is the obvious intent of the legislation. There may be some clarification needed; certainly that is something that will be looked at. I would anticipate it would be very rare you are going to need an advocate in a dentist's office. That would be certainly the intent that we would want to see drafted in the legislation.

1030

**Mr Sterling:** In fairness to the presenter, then, in what circumstances will he need an advocate?

**Mr Wessenger:** I think it would be a rare occasion, with a child who was of a sufficient age and who had some communication problem—there may be some rare examples, and I will ask our advisers.

**Ms Auksi:** Just to follow up on the comment I made earlier, there is a presumption of incapacity in children under 16. The feeling, then, is that there certainly are people—and the public health people have told us in droves—especially 12 and up and so on, who are evolving the capacity to make their own treatment decisions. The common law suggests that the principle is that if you have the mental capacity to make your own decision, then it is your right to do so.

The intent of what is in Bill 109 is to say that if you are demonstrating a wish to make that decision, the practitioner would have to assess whether you are capable or not. If you are capable of making that treatment decision—not all decisions of whatever kind, or even all treatment decisions, but that treatment decision—then the practitioner can take your consent.

For example, if you had a 13-year-old and the parent was not around but that 13-year-old was quite capable of consenting to the procedure himself, then that 13-year-old's consent would be sufficient. If the person has demonstrated the wish to make his own treatment decision and you assess and find that person incapable, then that is the point at which the act triggers certain rights protections, because he may want to object to that finding of incapacity because he has said he wants to make the decision. You have said, "You're not capable to make that decision." If they want to dispute that finding, that would be their right under this act.

As I said before, I think it is fair to say that the intent was not to pull into that provision four-year-olds who are just afraid and probably have no notion of consent at all. That is not the intent.

**Dr Maltz:** I understand that, but I have a problem. Let's just say an eight-year-old comes in who has to have a tooth fixed, or let's just say it is an emergency; he has a toothache. I say, "I want to fix that tooth." He says, "No, I don't want it fixed." I say, "It's going to hurt again tonight; it's not hurting now." He says, "I don't care; I don't want it fixed." That is where the problem comes in. He understands the implications, but he does not want to act on it.

**Ms Auksi:** But does that person really understand the risks and benefits and appreciate the consequences of refus-

ing consent in the sense that you would really need to, in order to give an informed consent or to refuse?

**Dr Maltz:** But it is not really clear; that is my problem.

**Ms Auksi:** Okay. I think the question that really lingers here is at what point might someone who is young maybe have some right to assert that right, and where it might be so obvious that they would not be.

**Dr Maltz:** I think basically, as a generalization, around the age of 12. Even if a 12-year-old came into the office right now and wanted to have something done, I would still get consent of the parent if it was anything at all invasive. In other words, if somebody came in and said, "Listen, my tooth has been bothering me; can you have a look at this?" that is fine. If I require to do any treatment or give the child any medication, I would have to get consent of either an adult, a guardian or an advocate.

The problem I see from a dental point of view—

**Ms Auksi:** I am sorry, an advocate does not—

**Dr Maltz:** No, no, no. I am just saying the problem, as I see it right now, is that things are not clear. There are going to be right now some 12-year-olds, and there may even be some 10-year-olds—the problem, as I see it, is the definition of understanding you can be capable as to one act and incapable as to another act. I think children of even 10 years old understand the implications of fillings, but they may not want to act on it. They do not want the short-term pain for the long-term gain; that is the decision they seem to be making.

**Ms Auksi:** I think that brings up the issue, too, of the assessment of capacity. It is recognized that when you are talking of the maturational process, people will say that in young people it is not just whether they have the cognitive ability per se, but whether they have reached a maturational level that would enable them to look ahead.

**Dr Maltz:** I think that has to be clarified.

**Mr Sterling:** We are sending him away, and under the present act, if an eight-year-old comes in with his mother and Johnny says no but mom says yes, what does the dentist do? The dentist, under the present legislation, has to call in an advocate, if he can find one. It costs mom more money, because she has to go through this thing twice. What is the answer? Is the government saying that somebody under a certain age is going to be deemed within the control of the parent alone and the parent shall make the decision, or not? That is the answer we need. What is your position, Mr Wessenger?

**Mr Wessenger:** I think we want to make it clear to people that—

**Mr Sterling:** Do make it clear, please.

**Mr Wessenger:** I think that is what we intend to do after these hearings have taken place.

**Mr Sterling:** No, no, it is your legislation, Mr Wessenger. You have an obligation to make it clear to the public what your position is.

**Mr Winner:** Why do you not let him reply, for starters?

**Mr Sterling:** Because I know what his reply is going to be.

**Mr Wessinger:** All the people we are listening to, people making these presentations—that is the purpose of these proceedings: to hear the areas of concern with respect to legislation, then to take all these areas of concern and to make sure the legislation, as it is finally brought forward, takes account of these concerns. I think that is the whole purpose. We are here today to hear from you, and I appreciate your coming and bringing us your concerns, because we certainly do not want to have the situation arising which you mentioned.

**Dr Maltz:** I understand that.

**The Chair:** Dr Maltz, on behalf of the committee, I would like to thank you for taking the time out this morning to give us your presentation.

**Dr Maltz:** Thank you very much.

ONTARIO PSYCHIATRIC SURVIVORS  
ALLIANCE - METRO TORONTO CHAPTER

**The Chair:** I would like to call forward the Ontario Psychiatric Survivors Alliance for Metro. Good morning. Could you please identify yourself for the record and then proceed.

**Ms Benmosche:** Good morning. My name is Shoshannah Benmosche. I am a member of the Metro Toronto chapter of the Ontario Psychiatric Survivors Alliance.

The Ontario Psychiatric Survivors Alliance is a self-help, non-profit organization dedicated to the empowerment, representation and wellbeing of all psychiatric survivors residing in Ontario. We advocate on behalf of the interests of psychiatric survivors through the development of local groups and individuals.

OPSA promotes greater survivor participation in managing the mental health system, as well as building alternative resources to fill those needs defined by members. We believe that psychiatric survivors are entitled to all the rights and obligations of citizenship, including those of choice, freedom, autonomy and access to alternatives. We will endeavour to advocate for these rights.

OPSA shall cooperate with groups having a similar aim and purpose, to work towards the achievement of our common goals. OPSA will always be highly responsive and responsible to its members.

We are in support of the submissions to the standing committee from the Ontario Advocacy Coalition and from the Ottawa chapter of the Ontario Psychiatric Survivors Alliance. We are also in support of the submissions from Irit Shimrat and Randy Pritchard of the provincial office of OPSA. We are grateful to Don Weitz for his valuable input to this committee. We thank the committee for this opportunity to present our views.

We have some concerns about how the Advocacy Commission will be formed and the criteria that should be applied in selecting commission members. We also have concerns about the selection process for advocates. Our important considerations are personal suitability, experience and training. Recognition should be made that caregiving professionals, such as social workers and adult

protection service workers, have little or no training in advocacy work, though some of them have become proficient in this area, usually in the face of opposition from the majority of their peers and superiors who favour more patronizing approaches.

It almost goes without saying that physicians or psychiatrists, as a group, have no experience in the area of advocacy and no training or expertise in the area of assessing competence. A legal test such as the Weisstub criteria should be universally applied by trained assessors. Those professionals who have engaged in advocacy work with their clients likely did so unofficially and beyond their mandate.

Traditionally, service providers who engage in advocacy have been in a minority and have been marginalized by their colleagues. They are often seen as threatening by the majority of professionals, who of course would like to believe the system in which they work is working and has no need for advocates. There exist professional care givers with appropriate experience and a client-centred orientation who through specialized training would make excellent advocates. It is far more likely, however, that consumer survivor groups with a specific mandate to advocate for their constituent community could provide or recommend a significant and important number of very good candidates. Many of them have the equivalent of doctoral degrees in life experience from the university of adversity.

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During the hearings on the legislation, professional groups have said, "Don't forget, we are advocates too." The professional community, in making such assertions, reveals its own misunderstandings about the need for advocates as well as the role of advocates. There are also many professionals who want to be advocates and would like to think of themselves as such. It is natural for professionals to say: "You don't have to worry about us. We're there to act in the patient's or client's best interests." The best-interests school of thought has contributed enormously to the types of abuse and neglect that have made advocacy legislation necessary to protect the rights of vulnerable people, people who are often made more vulnerable by professionals, friends or family members acting in the person's best interests. This is not to devalue the efforts of relatives and professionals who endeavour to support the vulnerable person's own expressed wishes and needs.

OPSA Metro recognizes the need for and the value of peer advocacy and self-advocacy. We know our power to advocate for ourselves is situationally determined. There is a power inequity between individuals and institutions. Access to being heard, to choice, to legal services, etc, is barred to those who do not know what is available. In the absence of options there can be no choice.

What a client needs is frequently in conflict with the services an institution is offering or is prepared to offer. I sat in at the offices of the Durham Board of Education before it would admit the services it had to offer were inappropriate to my gifted and dyslexic child's needs. I was required to prove the services were not available in order that they could be purchased from a neighbouring school board.

A Ministry of Health official recently advised, in a meeting a couple of weeks ago, that over 70% of the OHIP billings by psychiatrists is for psychotherapy. Surveys of psychiatric survivors indicate most patients would be very pleased if they could find a psychiatrist who would actively listen to them for at least an hour per week and collaboratively address their issues, rather than mystify and medicalize them and pass out debilitating and addictive drugs to make the patient manageable. If the patient bows to this neglect or abuse, he or she quickly gains the smiling approval of attending professionals and often of families who have a difficult time dealing with emotional distress and find disabling drugs preferable.

An honest survey of psychiatrists would reveal that most of them do not believe in the efficacy of psychotherapy, let alone practise it. If the moneys from these fraudulent OHIP billings were redirected, they would probably pay for an advocacy system several times over.

Family members who are in conflict with a vulnerable service recipient often like to present themselves as advocates. There is often a conflict of interest. Here too, a best-interests approach is often applied. It is natural that in such a situation the family member may see the intervention of an advocate as threatening or intrusive. In the psychiatric community, many consumer survivors have experienced a de facto collusion between professionals and family members to do what is best for the patient without consulting the patient in a way that is non-coercive and invites openness and free expression.

The patient often feels constrained by desires to make the family member happy and to be a good patient, often to his own detriment and harm. A skilful and client-oriented advocate will have the ability to win and deserve the trust of the patient in these situations; not an easy task. He or she must be able to elicit from the service recipient what they really want and need, and empower them to access these needs and desires.

Fifteen minutes is not long enough to scold you into remembering the evolution of this legislation, that it was sown by the current opposition, developed by it when the NDP was in opposition and trying to be the conscience of Ontario. Now it is the opposition's turn and our conscience is reduced to bucks. Is it not time the buck stopped here?

There is a scriptural adage to the effect that if you are responsible for what you have, more will be given you; if you are not, it will be taken away. The funds we have at our disposal will always be limited. Whatever the amounts are, we have to make responsible decisions. It is not responsible to continue to fund things that impact negatively on the community purportedly being served. The need for instructed, non-instructed and systemic advocacy is uncontested by disempowered persons. Power inequities will always exist and need to be mitigated in a healthy, compassionate and just society.

We are able to establish minimum standards for the treatment of animals; we remove those that are mistreated from their owners. There are standards for prisoners, even prisoners of war held captive by hated enemies. These standards prescribe the need for light, air, exercise, potable water, nourishment and medical attention. We recognize

abuses, torture, starvation, dehydration, physical and psychological cruelty. Are we unable to recognize and require by regulation the right of access to minimum standards of wellbeing for all persons? At the same time, it is important not to impose unwanted standards and values on individuals who, for instance, prefer privacy to clean floors.

Many arenas of power inequity mitigate against our needs being perceived and met. Our warm bodies are fodder for many powerful mills. We are coerced and deliberately misinformed by the very agents required by law to inform us. Disabled persons, especially children, are vulnerable to chemical and surgical experimentation deliberately disguised as therapeutic procedure on consent forms. The occurrence of informed consent is virtually non-existent in Ontario's mental health system, despite legislation that has been on the books for many years. I would suggest a lot of advocacy is required to implement existing law and see if it can be made to work for the people it purports to protect.

We need advocacy urgently and would like to see the supporting legislation improved prior to the implementation of these acts. Advocacy should provide an ongoing mechanism for access, accountability and correction. Advocacy for those who are unable to advocate for themselves effectively without assistance is the single most essential component of an ongoing mechanism to ensure the administration of a recognizable justice, the meeting of needs, the acquisition of rights and the healing of society.

I am concerned about the pricetag for advocacy being a loss of long-term rights in exchange for the meeting of immediate needs. For example, the burden of proof that I am human and have the right to determine my own self-interest, make informed choices and act upon my own hierarchy of values should not shift to anyone else as soon as I explore medical options and become classed as a patient. Due process to determine my incompetence must assure that the burden of proof rests with the legal, not medical, assessment of incompetence. The only exceptions intended by the proposed legislation are for saving life and limb where emergency medical intervention is required to do so and the patient is unconscious. The need for an advocacy system arises from a belief among professionals that they know better than we ourselves what our needs are and what our values ought to be. The shape of the administration of advocacy will also have to be accountable to the community it is constructed to serve.

Right now, all of us sitting at this table, all of us sitting around the room, are and have been involved in a process together. Many factors in this process have presented us all with obstacles and obstructions in the way of our achieving what we have set out to do. Empowerment is what this process is all about. Empowerment is what this legislation is all about. Many are threatened when we discuss power. The knee-jerk reaction of many professionals, many institutions and even many family members is to ensure that empowering vulnerable people will not diminish the power of some of us, who have found access to it easier than many of us.

We have witnessed the defensive posture of both families and professionals in response to this legislation, even the esteemed College of Physicians and Surgeons of Ontario.

It is disheartening but not surprising to many psychiatric survivors that the college has not taken the initiative or the opportunity to monitor and regulate that specialty within its sphere that has caused the medical profession more public embarrassment than any other discipline: the field of psychiatry.

Instead, the college has maintained the silence of the old boys' club. Instead, the college presents us with nightmarish scenarios in which doctors are not able to diagnose and treat children who may be afflicted with meningitis because they are restrained by the red tape of a bureaucracy by which they feel accused. It is difficult for a reasonable person to imagine that any physician could possibly believe the intent of advocacy legislation is to allow children to die. This not-so-veiled threat to withdraw essential services if the legislation is passed represents an obfuscation of the medical profession's true fear that questionable practices will come under the scrutiny of someone other than themselves.

#### 1050

Most of us who have survived the widespread systemic abuse and neglect of the psychiatric system are able to recognize the good intentions of many health care professionals. Abuse and neglect often come from well-meaning but misguided caring people who have had years of training in the practices, theories and procedures from which abuse freely flows.

Mental health professionals are trained to treat criticism from patients as symptomatic of imagined illnesses. They have carefully guarded against learning anything from their personal experiences that might challenge cherished theories that are presented as fact. They have learned to treat individuals as if they were unaffected by environmental factors. In their efforts to be "real" doctors, they have reduced all emotional distress to chemical imbalances for which there are no scientific tests. They have become victims of their own professional indoctrination. Their usefulness to us is largely confined to signing forms we need to qualify for housing, vocational rehabilitation services, financial assistance and other government-funded programs and services. In order to access these services, we must often subject ourselves to 10-minute diagnoses, invalidation of our feelings, experiences and selves, long-term addiction and lifetime prescriptions of drugs that are more disabling than our so-called illnesses.

The efficacy of medication is usually judged by how well we are observed to behave by professionals and family members. How we behave becomes more important than how we feel, and there is great pressure on us to say we feel fine, if only to avoid further abuse. It is difficult to misbehave when given drugs that make it extremely difficult to process information and which make it difficult to move. Outsiders, even psychiatric professionals, often choose to see drug effects as further symptoms of illness. There are so many diagnoses in the DSM-3 that it is not surprising many of us have several labels assigned by as many psychiatrists.

We recognize that even professional care givers are subject to the abuses of a mental health system that is largely controlled by drug companies, and by the damag-

ing effect of pseudo-scientific arguments aimed at legitimizing the treatment of non-medical problems by medical means. The psychiatric disciplines have fought hard to gain the legitimate respect of other medical specialties, largely by playing doctor. They have been accepted and have been offered unquestioning shelter by the College of Physicians and Surgeons, despite offering treatments that are extremely harmful, despite arrogant refusal in the face of the law to seek informed consent, especially when offering treatment that presents consequences that are dangerous to their patients.

We are aware that psychiatric residents in training are systematically dumped from programs when they refuse to perform procedures they have determined to be unhelpful, dangerous, abusive and/or neglectful. Some have referred to these practices as initiation rites. Had the College of Physicians and Surgeons taken the responsibility for the abuse that has passed for so long as care and treatment, we would have little need for advocacy legislation. To the degree the college accepts this responsibility in the future, it will have fewer complaints from patients and fewer advocate interventions. Where self-regulation works, as seldom as this is the case, there is little or no need for advocacy.

This committee has heard presentations from desperate relatives who spoke as individuals but some of whom are members of an organization which calls itself Friends of Schizophrenics, an organization established to protect the rights of psychiatrists to impose treatment against the will of patients who exhibit such symptoms as imagining that electroshock and drugs which paralyse their central nervous systems and thought processes are not good for them and make them feel terrible.

Friends of Schizophrenics of course receives a great deal of support from drug companies and psychiatrists who assure family members that resisting treatment is symptomatic of the illness with which their loved one is afflicted. Many of the personal stories of family members are quite sad and touching. It is very difficult to live with and care for a relative who is going through emotional hell. Family members are vulnerable to professionals who baffle them with psychobabble and promote what many survivors of such dangerous treatment recognize as institutional substance abuse.

For every horror story of someone committing suicide because they refused medication, there are hundreds of good patients who always did what the doctor said to do, whose conditions worsened, who experienced the soul-murdering effects of neuroleptic drugs, who lost hope when drug-pushing psychiatry, the only game in town, seemed to have nothing to offer, who slipped away and died in despair, still good patients, taking their meds for the last time.

Many survivors have experienced times when we have been in need of a safe place to go, often for our own protection. The help we ask for has not been the help we get. The institutions established by our society have proven not to be safe places. When we need to be listened to, we are shut up. When we arrive with a presenting problem, we are patronized, labelled and given the message that our perceived problems are non-existent or less important than those the professionals would like to treat.

We would like to have the choice to refuse treatment we find inappropriate without being discharged for refusing treatment. Many, though not all of us, would like some help in sorting out the problems we face without subjecting ourselves to dangerous drugs. There is a legitimate place for psychotherapy and a need for it to be covered by OHIP. Psychotherapy is available from psychologists, but this is not covered by OHIP. Many of us could have our needs met through psychosocial counselling, which is usually only available to patients who are willing to subject themselves to more intrusive and disabling treatments at the same time. We need more choices.

"Empowerment" has become a nice word. In becoming a nice word, it has its meaning in a paternalistic system. It has not, however, lost its meaning for those of us who have experienced the nature of power from the vantage point of powerlessness. Like health, we hope to regain it. Those of us who have lived throughout powerlessness, who have learned to advocate for ourselves against tremendous odds, are more than just stakeholders in a system.

We and our needs are the *raison d'être* for the system. If it continues to fail us, if we allow it to fail us, everybody loses. We are the most important part of the equation, not just in the development of this legislation but finally in its implementation. We affirm our right to be part of the solution. Without us there is no solution.

Advocacy cannot exist without empowerment. It is the exclusive role of the powerless to define empowerment. It cannot be defined for us by experts of any description. Empowerment inflicted is empowerment lost. We must ensure the continued involvement of those this legislation is designed to protect. They must constitute the Advocacy Commission and must be actively involved in the shaping of policies and procedures which will govern the implementation of the Advocacy Act. Many representatives of consumer/survivor groups in the labelled and disabled communities have years of experience in advocacy and should be hired as advocates.

We are now at a stage where precise wording of a bill is being discussed and considered. We are in the midst of the trees as we examine each of them. We are now sharing in our very difficult struggle to maintain our view of the forest. We stand on the threshold, on the brink of the final outcome which will determine whether our involvement, our taking ownership of the crying need for a more caring and responsive social environment, whether the struggle of disempowered people acting in a collaborative effort with government and institutions to take what is ours, to get our share, will contribute to our ultimate empowerment, further encouraging us to own our lives, to take our rightful place in our society.

The people OPSA represents, survivors of an inadequate and disempowering mental health system, have long had faith in this government's intention to do what a former NDP MPP described as "doing the right thing right." This faith has been challenged by the time and effort we have had to invest in this process, by the hopes we have invested and the personal risks we take just to keep the government on track. One of our members, feeling the frustration shared by many of us in regard to helping to

give shape and life to this legislation, made an interesting observation, "If the government is unable to do the right thing right, can't at least do the left thing right?"

1100

And right now, at these hearings, we have come to the crunches, the final hour for you to decide whether this administration will properly use the power the electorate gave it to do something good that may outlive this government. We need advocacy. The pricetag in dollars is not the main consideration here.

It comes down to supporting the status quo, appeasing those who have the power now, or doing what is the true function of government in a democratic society, of redistributing the power pot to ensure inclusion, access and participation by all members of society to the extent they want to participate. Right now we are not consumers; we are a commodity, frequently a liability and a frustration to people who feel the need to control us, to shut us up and shut us out. The cost in human waste is enormous. We are kept alive without hope. The human rights commissions were swamped with claims from disabled persons who were experiencing the natural response of our society to vulnerable persons: further victimization of victims. Human rights officers were not trained advocates and they were not experiential peers of the labelled and disabled, and they could not identify with their needs to begin to meet them.

I have experience both as a survivor and as a parent of a vulnerable person. My story is not typical, only because I am an escapee. My caring family could not cope with me when my hormones and my angers exploded in my early teens. They were dismayed by my politics. They were disgusted by my taste in clothing, friends, music, philosophies, my attraction to various religious speculations on the nature of reality and my uncompromising rejection of their sexist, paternalistic religion and my intolerance of their hypocrisies. They did not like me. I embarrassed them. The clincher was that they were threatened by my recollections of sexual abuse. My mother would not admit that it could have happened. Her primary concern was my father's health. For their own protection, I was psychiatrized and they were supported in their preferred belief that it was a demented fantasy of mine. The first validation of my experiences came from my sister many years later. This validation was more therapeutic than anything I experienced in the mental health system. Somehow, even without validation, I managed to reject the assertions of the psychiatrists that my memories were fabrications, symptomatic of illness. I have forgiven my parents for being normal, inadequate as parents and lacking courage. My father was not courageous enough to admit his weaknesses and my mother was powerless to protect me from his abuse.

In the mid-1950s, adults were more likely to be prescribed drugs and electroconvulsive therapy and insulin shock treatment than were children. This is not the situation today, where increasingly younger children are the subject of experimentation. I was lucky. My age protected me from the kinds of abuse that are euphemized as "care" and "treatment" in Ontario today. I learned about humiliation,

coercion, and I survived the system. Some of my friends were turned into vegetables and one of them died as a result of the "therapeutic treatment" he received at the same hospital. He was only a few months older than I but he was on an adult ward. Excuse me.

Feelings, experiences, memories and ultimately people are made waste, negated and invalidated in a process that to me constitutes the most horrific abuse imaginable. It is difficult for most people who have not experienced Ontario's mental health system to accept and believe that abuse and neglect are not the exception but the rule. This will not stop the ever-growing numbers of survivors who insist on telling the truth regardless of how uncomfortable it makes well-meaning people who wear blinders.

The treatment of my friends in 1992 Toronto hospitals is worse than the treatment I received. Today, children are more likely to become subjects of experiments and treated to cruel and unusual injustices and indignities. This legislation must also protect children. Physically or sexually abused women, through the magic of psychiatry, are diagnosed with chemical imbalances which somehow explain their being victims. Chemical imbalances can be determined by psychiatrists via five-minute conversations—no blood tests. Normal people are unable to achieve this. Some sceptics think it is a scam but most people believe the psychiatrists. We all need someone to believe in.

Disabled and labelled people, survivors, acting collectively, are beginning to believe in themselves. We are discovering that learning to be assertive is therapeutic; that getting what we need and want in our lives, by reclaiming what is ours, we contribute to our own healing. We ask—no, we demand that this government honour its long-standing commitment to the underdog by strengthening and passing this legislation to provide advocacy services for all vulnerable people in Ontario. Thank you.

I would like to introduce you to Marianne Weberschar. She is a member of Metro OPSA.

**The Chair:** Thank you. The presentation took a half-hour, but I will allow very brief questioning if anyone would like to.

**Ms Benmosche':** I am sorry.

**The Chair:** Mr Wilson?

**Mr Wilson:** It was pretty thorough, Mr Chair.

**The Chair:** Mrs Carter, very briefly.

**Ms Carter:** I would like to thank you for a very powerful and moving presentation. I just want to underline once more that the idea behind the advocates that we are proposing in this bill is that they be listeners, that they go to vulnerable people, hear what they have to say. They are not in any way decision-makers. Their job is to act on what they have been told that person wants.

I also draw your attention to section 15 of Bill 74, which lists the categories of people who are going to be on the appointments advisory committee. The emphasis is definitely on getting people who have been there. It is not, obviously, just psychiatric providers. People with other kinds of vulnerability are going to be very heavily represented on that committee. We are not looking at an army of very highly professionalized people going around and tell-

ing people what is good for them. We are doing quite the opposite.

Having said that, I would like to ask you in what ways the bill could be strengthened and improved, because you seem to be going along with it but saying that perhaps there is not enough there, perhaps we could do more.

**Ms Benmosche':** I do not see that there is a mandate for client-centredness there. The only way we can protect that is if the commission is primarily disabled persons, peers of the people they represent.

**Ms Carter:** That is what is said.

**Ms Benmosche':** It says that, but there is not any requirement that elected persons, who are elected by constituent groups to represent them, will necessarily be appointed. I am not so concerned with the advocacy legislation as it is presented. I am concerned about the order of default in substitute decision-making. I am concerned with the intent not being manifest in the law about the protection of doctors to do things. Unfortunately there will not be a problem with advocates. Advocates are listeners; they are not decision-makers.

**Ms Carter:** But they also have the power to go out and change the system. That is the other aspect of what they will do.

1110

**Ms Benmosche':** Where you have laws that are inappropriate they have to be redressed. Unfortunately, governments seem to act very quickly, when decisions are made, to mitigate against the intent of those decisions. We had a decision in the Swain case, and as far as I know we still do not have anything approximating compliance with the charter for people who do not choose to be tried, who are incapable. They cannot be acquitted; under what has been proposed, they could not be acquitted of a crime. They could only be in some sort of limbo situation.

**Mr Malkowski:** I want to thank you for your presentation. I think it had a very big impact, and it is time for us to listen to those consumers who have experienced it. They can be a great resource for us. I just want to know if you are aware that the commission will be receiving nominations from various organization such as yours, the survivors alliance. They will be submitting the names to the commission. I wonder if you feel that is enough as far as consumer control goes, or if you have any other recommendations to improve that part of the legislation.

**Ms Benmosche':** No, I am quite satisfied. I just want to reiterate the importance of keeping it client-centred and not use representatives from organizations that were not composed of their disabled constituency. There is nobody who can better represent somebody than themselves, even if they need an interpreter or if they need someone sensitive to their issues to verbalize it for them when they are not able to be articulate.

That does not mean they are not able to communicate. They are able to communicate in a trusted situation what their desires are, but they cannot always represent themselves well. They are also in very vulnerable situations. The more vulnerable people are, the more dependent they

are on others, the more they are constrained from asking for things that they do not think they are going to be able to get or that is going to bring the wrath of their providers down on them. They are needy. They need to be protected.

**The Chair:** I want like to thank you on behalf of the committee for coming forward and giving your presentation.

#### MEMORIAL UNIVERSITY OF NEWFOUNDLAND

**The Chair:** I would like to call forward our next presenter, Professor Morris Saldov. Please identify yourself for the record and then proceed.

**Dr Saldov:** My name is Morris Saldov, professor of social policy and community development at Memorial University of Newfoundland. My goal here today is to speak first on a personal level regarding the requirements of the ethnic elderly, then to go on to discuss some research that I did in Toronto during my sabbatical year on the needs of ethnic elderly in health care institution, and then go on to make comments, hopefully constructive suggestions, regarding the legislation.

"Ethnic elderly" means those who are over 65 and speak little or no English. I want to start with a personal story. My mother-in-law is a Chinese elderly, 85 years old. Her name is Popo, which is Chinese for "grandmother." She has raised four adopted children, one of whom is my wife. She is blind, she has a hip replacement and she speaks no English. Popo deserves the best treatment that our health care system can offer. What I am about to relate is a true story.

About a year ago, Popo developed pneumonia while I was her primary care giver during my sabbatical. At that time my wife and daughter were in Indonesia, and I made the decision to admit her to a local hospital which boasted a transcultural health care program. It is on the periphery of Chinatown in Toronto. She was admitted through the emergency ward of the hospital. For the period of about three hours, while she was going through various investigative procedures, no interpreter was available. Therefore, I was the only person able, in a limited way, to convey to her some of the meaning of what was going on, describe some of the procedures that were taken.

First of all the doctor appeared, lifted her blouse and put a cold object, which is a stethoscope, on her back. I do not know the technical term for "stethoscope" in Chinese and I am not sure that many Chinese know what that is, but imagine that you are blind and that you do not speak a word of English and someone comes in and lifts up your blouse and puts something cold on your back without telling you what that is.

The next thing, someone comes in and holds your arm and sticks a needle in it, without telling you what he or she is doing, because he needs a blood sample. The next thing you know you are on a cart off to somewhere, you do not know where, and you are put with your chest against a very cold object, again, and an X-ray is taken. You have no one explaining to you what is going on.

You need treatment, so the immediate thing is to get chemicals into your body to correct some of the dehydration. An intravenous is inserted into your arm, again with no explanation of what is going on. There is an inordinate

amount of screaming that is going on during the course of this and an awful lot of anguish on my part, and of course on Popo's part.

Popo does not understand what IV is, and certainly she did not understand when it was inserted without any explanation. She felt this cold object on her arm that was causing her some pain and proceeded several times to remove it. Of course then the nurse had to come in and reinsert it several times. I had to walk out at one point, I was so anguished by the whole procedure.

This is not the only time that Popo has been admitted to hospital. When she broke her hip more than a year and a half ago, she spent six months in hospital. My wife, my daughter and I spent almost 24 hours a day on rotating shifts to protect her from the hospital. There were times when nurses would come in to perform an enema when she did not need one and there was no one there to explain. If we had not been there, she would have had an enema performed on her without anyone explaining what was about to occur. Just imagine that.

At another time they did not understand when she called for the bedpan or when she called to go to the washroom, so what did they do? They put diapers on her. You come in, you pull the person's pants down, you start manipulating her underparts and she ends up with a diaper on. Imagine if you had that done to you when you were blind and no one had told you what they were doing. Presumably you would feel you were being assaulted. That is what Popo felt and she screamed. This would occur repeatedly with no one to explain what was going on.

If you are a Chinese elderly and you come from mainland China, wetness has a particular significance to you because flooding in China is one of the most serious disasters that has occurred. Popo is very sensitive to wetness. It reminds her of flooding. She has had her house flooded many times and many people have died in floods, so when she was wet in a diaper the significance of that was beyond what a lot of people might have imagined.

Popo, after spending several months in the hospital, deteriorated significantly, and it took us the best part of the year to restore what I would call her mental status, her ability to respond to people. She withdrew even when we were there a lot of the time. We could not be there all the time, and when we were not, there were things that happened to her similar to what I have just described.

These experiences led me to join forces with a colleague, a Dr Peter Chow, who was also at Memorial University at the time and who has since moved to the University of Lethbridge. We both agreed that this was an area that required some investigation. We needed to have a sense of the proportion of this problem in the hospitals, nursing homes and homes for the aged in Toronto. We undertook to do a study, which was conducted in December 1990.

#### 1120

I want to share with you now the results of that study. A majority of the respondents, 77%, were from hospitals, with 13% coming from homes for the aged and the remainder from nursing homes. These were health care workers who were asked about the extent of the problem and the number of ethnic elderly under their care and what types

of services they had provided in order to help overcome the communication barriers between ethnic elderly and their care providers.

In general, acute-care clients received more interpreter services than chronic-care patients, from staff, family members, friends and other sources. About 50% of all the ethnic elderly had few non-critical problems caused by their lack of ability to speak English; 20% had some problems that if unresolved they could become critical, and for 10% of the ethnic elderly communication was critical to their health care. A majority of the health care settings, 83%, reported having some type of interpreter service, while 9% said that none was available.

Many agencies found other methods to provide linguistic and cultural services, including extending visiting hours for family, friends and other visitors, 83% of the sample; reliance on free interpreter services from community-based ethnic agencies was also present, 21%; volunteer interpreters, 39% of the sample; matching ethnic staff assignments to ethnic elderly from the same background, 44%; matching ethnic patients with similar ethnic backgrounds at least one of whom speaks English, 60%; calling on ethnic staff or patients for interpreter services from other wards or rooms when needed, 91%; hiring staff to reflect the various linguistic backgrounds of residents and/or patients, 35%; relying on family members to provide interpreter services to other ethnic elderly, 58%, and using technologies like diagrams, photographs or other means for communication, 71%. Only 12% reported that training was available for developing ethnic sensitivity in health care delivery, while 18% indicated that staff workshops were being planned. Few agencies, 14%, had a separate budget for interpreter services.

What we see here is a picture of a health care system that recognizes that there is a problem in communicating with ethnic elderly but where funding is very insignificantly provided for interpreter services—linguistic and cultural—to the tune of 14%. The recognition that the problem exists is reflected in the fact that most of these health care agencies have provided ad hoc interpreter services, relied on family members, staff or perhaps kitchen staff or relied on others—other relatives visiting or church members or other volunteers in the community. So what you get is a patchwork of ad hocery in dealing with what is a very significant and serious problem.

In 1987, the Social Planning Council of Metropolitan Toronto did a study on access to health care and social services in Ontario. What they found was that where there were communication barriers, there were some serious restrictions and limitations on the access to health care, which resulted in numerous inefficiencies, numerous examples of ineffectiveness and certainly problems with equity in the delivery of health care. The implications of our findings and of the findings of the social planning council, the many family members and the clients themselves, the ethnic elderly, for your legislation are specific to the issue in question of ensuring that there is no communication barrier for those clients who are in need of advocacy and services in the health care system.

But specifically, I wish to refer to Bill 74, clauses 7(1)(b) and 7(1)(f). Clause 7(1)(f) says: "ensure that advocacy services are provided in a manner that takes into account the religion, culture and traditions of vulnerable persons." I would suggest that you add "language" following "culture" to ensure that language is not a barrier in the provision of advocacy services. There is nothing in here that would guarantee that a person would be provided with interpreter services in the delivery of advocacy.

Second, subsection 9(1) on the next page says, "No proceeding for damages shall be instituted against a member of the commission or an advocate or other person who works for the commission or in a community program, whether on a paid or voluntary basis, for any act done in good faith"—I underline that—"in the execution or intended execution of the person's duty or for any alleged neglect or default in the execution in good faith of the person's duty."

This reminds me of the provisions in the medical profession today that do not provide for malpractice suits unless malice can be shown, which is different from the American system. I guess what this allows for is neglect to occur, not only in the health care system but on the part of advocacy services, as long as the intent was good.

I would suggest that if we look at some of the mission statements of hospitals today, Mount Sinai Hospital in particular, there is a well-developed mission statement which says that we shall treat everyone equally, to the best of our available resources. At the same time they say we must be sensitive to cultural differences. There is an apparent contradiction there. You cannot treat people who are not equal in the same manner and expect that the outcomes will be equal. So one particular philosophy of treatment, that which requires equality, conflicts with a more affirmative action type of approach or a positive discrimination for ways of arriving at more equality in the outcome.

My concern is that "in good faith" may not be sufficient when we have statements of mission which do not respond adequately to the needs of particularly vulnerable groups like the ethnic elderly. I am not sure how you would change the act to deal with that. All I do is call that to your attention. We would have to look very carefully at what we mean by "in good faith" and "with good intentions." We have heard the expression. With good intentions, hell is proverbially paved. Maybe that is what I am speaking to.

I now wish to move to informed consent and simply point out again that a vulnerable person who does not have the means to communicate consent is doubly vulnerable. This speaks again to the need for interpreter services for the ethnic elderly and others who may not be able to speak the language of their care givers or the language of the advocate who is apparently working with them.

That is all I had to contribute today, and I am prepared to respond to questions.

**Mr Poirier:** I was listening to your comments and, being a Franco-Ontarian, I could have applied them to one of Canada's official languages. The same thing happens still very much. Yesterday, I wanted to give a copy to the parliamentary assistant to the Minister of Health showing where my good friend Chantal Hébert, who is the reporter

for Le Devoir based in Ottawa, needed medical services for herself in an Ottawa hospital but also needed veterinary services for her cat. Her observation in 1992 was that when she went to the vet's place for her cat, they asked her if her cat was able to understand commands in English or French. She got better service in French for her cat than she got for herself in the hospital. So I understand where you are coming from.

Hell, there was a 1976 Dubois report that decried the lack of services available for elderly francophones and for children in the children's hospital; I guess a place like Toronto's Sick Kids, with a horrible name like that. It is still happening, and I can understand why you would come forward today. This type of thing is happening to francophones also and to multiethnic groups. Goodwill—we are used to that. We know very much where goodwill stands, especially on St Valentine's Day like this. I sympathize with you, and believe me, it must be a horrible feeling being elderly in that type of situation. I was putting myself in the shoes of your mother-in-law. It must have been a bloody horrible feeling to have that done, and it is still happening with the francophone community the very same way.

1130

**Dr Saldov:** The United Nations has declared Toronto the most multicultural city in the world, and that is very nice, but if we are to live up to that designation in Ontario, I think we have an obligation to provide the cultural and ethnic services that reflect that.

I visited Australia last summer, where I attended a conference in which the issue of services to ethnic elderly was very much on the agenda. I would like to report to you that in Australia, despite the absence of a Human Rights Code, they have what they call an ethnic link program, funded by the Commonwealth government, that ensures that any person who does not speak the language of his or her care providers or service providers is supplied with an interpreter at the expense of the state. That could be in health care institutions; that could be in the courtrooms; it could be in dealing with social services. In any service that is publicly funded, a free interpreter is provided, and not only for linguistic communication, but also for cultural interpretation. It is quite a statement to say that in a country that has no Human Rights Code, they have gone beyond what we have done with our Human Rights Code.

**Mr Poirier:** Sure, exactly. Words are very nice, but I would rather be judged by the actions that we do or do not do than the words we say or do not say. With what is happening to intolerance and the hardening of attitudes right now—we all know that in tough socioeconomic times, minorities and the other official language take it on the nose. It does not appear to be a very encouraging climate with the de-formers—I do not call them the Reformers but the de-formers—pushing for anti-multiculturalism, the Alliance for the Preservation of English in Canada with their attitudes against francophones and everything like that. Let's wish each other luck, my friend, because the climate is not that open, I guess, for that kind of situation.

**Dr Saldov:** Which suggests that we have to work that much harder—

**Mr Poirier:** You got it.

**Dr Saldov:** —to counter a force that is moving to the right in its intolerance to different races.

**Mr Poirier:** Far right.

**Mr J. Wilson:** I resent the conversation that just took place, that anyone on the far right is somehow not compassionate or sensitive to multiculturalism or the need for linguistic services. In fact, it might have been a government in the past that was to the right but had a very large dose of compassion and introduced the programs we enjoy today and managed those programs—

**Mr Winner:** Not in those areas.

**Mr J. Wilson:** For the left to think it has a corner on compassion is a misreading of history.

You raised an excellent point. My brothers-in-law are Chinese-Indonesian also, and my sister-in-law's mother has been in the hospital quite a few times. I know the family has had to do an around-the-clock vigil to make sure she understands, because she speaks very little English. So I have some understanding, although at a distance, of what you are going through.

My question, then, would be more to the government. The press release has a very good point, that advocates, particularly in Metropolitan Toronto, I would think, would have to be multilingual, certainly in both of Canada's official languages, I would think, and with the ethnic diversity in Toronto. I will maybe just make a statement. I would hate to see us having interpreters interpreting for the advocates who are speaking on behalf of the client. Maybe we could combine those services. I think the parliamentary assistant, Mr Wessinger, wants to comment on that.

**The Chair:** Do you want to comment on that?

**Mr Wessinger:** With this whole question, I understand that right now, under the Mental Health Act, there is currently funding available for interpreters for rights advice. You bring out the point that there is the same need in the other health care fields, and I would hope that would be addressed. The Ministry of Health does have a multicultural advisory committee which is advising with respect to this matter of the providing of services in multicultural settings, and there is a multicultural coordinator to look into these areas and bring forth the proper recommendations. So the matter is to our attention, but I agree with you that we need to address the problem. We are aware of it, but we really need to address it.

**Dr Saldov:** Two points that came out from both of your comments. First is that, yes, families frequently end up bearing much of the responsibility for interpreting, or other volunteers from the community or people visiting the hospital. What we found in the six months in 1990-91 is that there were increasing numbers of families who could not come to the hospital because they had two jobs. In a recession, I suspect that there are going to be more and more hardships on families and less time available unless funds are available for them to fund other professionals or support others going to the hospital. We found that to be a

very disturbing trend, particularly in the Chinese community, where family is a very strong institution.

The second thing is that interpreters, which exist in some hospitals such as Mount Sinai, are there from 9 to 5. They come for meetings, so if you are calling for the bedpan, forget it; you are not going get your bedpan. These are essential services that contribute to the wellbeing and the dignity of people who are under care. So formal interpreter services might be fine at meetings, but there needs to be some systematic way of ensuring that the care provided and the advocacy provided are ongoing, not only at prescribed times.

**Mr J. Wilson:** You mentioned the recession. I imagine it is difficult for the government to ensure that you can provide the linguistic services required, because it is a spiral. I find that some people out in the street tend to forget that the reason you are doing two jobs is you are the highest-taxed jurisdiction in North America. We add more services, we have to pay for them, so you may do three jobs. I mean, I know my own staff. I have two people who are working here every day, getting paid fairly good money, and taking a second job at night just to make ends meet. So the government will have to keep that in mind. You add more services; you have to pay for them, too.

**Mr Malkowski:** Your points about interpreting services are very important. It is really something I have been very sensitive to because I use interpreters, so your points hit home. It is access to information. That is what is important.

Another point, of course, when it comes to access to information is that doctors need the correct information in order to help the patient. In order to get the right care, the communication and the cultural interpretation and the linguistic interpretation have to come through for the physician as well. The goal, of course, is to improve the access to services with sensitivity to cultural and linguistic needs for equal treatment in the hospital service.

I agree with what you talked about in your situations. You demonstrated about having your mother-in-law, the blind lady, having the IV, and I know that is very true for people in the community who are blind, who have the same experiences at hospitals. So it is something we have heard about and we face, yes.

**Dr Saldov:** The Doyle and Visano study of 1987, which addressed the problems of access to multicultural communities of health and social services, found that costs were increased because of the absence of interpreter services. People would leave the hospital without the proper aftercare or instructions or understanding of the aftercare instructions, and so were readmitted to hospital. Doctors who did not understand their patients, either their cultural meanings of health or illness or the words they spoke, took much longer to diagnose, and therefore the patient had to stay in hospital much longer. So by the absence of interpreter services, we may in fact be increasing costs beyond what it would cost to have them.

**Mr J. Wilson:** It is a good point and well taken, because we find that, for instance, if we could move more towards community-based care, we would probably decrease costs. It is that initial injection of funds to get the system up and going that seems to be the barrier at the moment.

1140

**Ms Carter:** This is a very important question that you have raised. This bill is being put forward by the Ministry of Citizenship, which is also the ministry responsible for multicultural affairs.

On page 2 of Bill 74, section 1, there are two clauses where we are stating the purposes of the act which could be relevant: "(a) to contribute to the empowerment of vulnerable persons and to promote respect for their rights, freedoms, autonomy and dignity;" and then "(d) to take into account the religion, culture and traditions of vulnerable persons." Hopefully, if we interpret this in that spirit, then these needs should be taken into account. Your point that it may be cheaper in the long run is certainly a valid one.

Just a thought that occurred to me: For a basic need like a bedpan, could hospitals not have some kind of signalling system that could be explained to a person and then they would know?

**Dr Saldov:** We established a list of Chinese words with the English phonetics and hung it up at the bedside of our mother-in-law; however, several nurses did not see it as their responsibility to even look at that list.

**Ms Carter:** I see. They would not cooperate.

**Dr Saldov:** That is beyond their mandate and responsibility. The fact that they might learn those words because of the numbers of Chinese or Portuguese or Italians is not within their realm of responsibility. There is only one nursing home in Toronto that makes it its responsibility, and that is the Rekai Centre on Sherbourne Street where all staff must learn a short list of key words in order to ensure that patients are understood. It would be most helpful if that would be part of the job description, that you had to at least, if not learn the words, pay attention to a list of words in order to facilitate the care.

I appreciate the mention of section 1 regarding the purposes of the act, and you drew attention to clause 1(d) which asks that religion, culture and traditions of vulnerable persons be taken into account. It is not sufficient to say "culture and traditions." Language should be in there, because if we only look at culture, which is important in itself because it conveys certain meanings of health and illness, we do not necessarily have to pay attention to language. If I were drafting this legislation, I would want to include language.

**The Chair:** Mr Wessinger, do you have a brief comment or question?

**Mr Wessinger:** No, I do not.

**The Chair:** Okay. Dr Saldov, on behalf of the committee, I would like to thank you for taking the time out this morning and giving us your presentation.

**Dr Saldov:** Thank you.

TERRY L. F. PARKER

**The Chair:** I would like to call forward our next presenter, Terry Parker. Good morning.

**Mr Parker:** Good morning.

**The Chair:** Could you identify yourself for the record, and then please proceed.

**Mr Parker:** My name is Terry Parker, a resident of Toronto, also a member of APSAO. Dear ladies and gentlemen, members of the Legislature, may I express that what is needed here today is not An Act respecting Consent to Treatment but rather an act respecting consent to medical experimentation that has been purported to be a form of treatment. In other words, in general terms, there is no great public outcry when consenting to a drug or surgical treatment that is of sincere benefit for the patient's best interest and wellbeing. However, if drug or surgical experimentation is imposed without informed consent or parental knowledge and under the guise as being a form of treatment, one will discover public outcry, if not outrage.

When reading this bill, I am extremely offended when I read section 15, which states:

"Nothing in this act authorizes a health practitioner to perform any of the following procedures on a person who is incapable with respect to the procedure:

- "1. A procedure whose primary purpose is research.
- "2. Sterilization that is not medically necessary for the protection of the person's health.
- "3. The removal of regenerative or non-regenerative tissue for implantation in another person's body."

My chief concern is that although these procedures have been excluded from this bill, the fact remains that they have been carried out under the guise of being a form of medical treatment. As such, no provision or commission is available to the public to provide a fair, impartial review of experimental procedures carried out under the guise of a medical treatment.

To demonstrate my point, I have provided the committee with the following documentation to support my position:

1. A 1972 consent form and present consent form used by the Hospital for Sick Children;
2. A letter from my mother, Mrs Helen Cork, submitted to a Dr Hoffman dated July 22, 1989;
3. A letter from my former attorney, Ms Marlys Edwardh, to the area director of legal aid, dated October 6, 1977;
4. A newsletter by Dr Peter Breggin, dated October 1973, outlining current psychosurgery in Canada;
5. Protocol and consent forms pertaining to the marijuana/epilepsy study;
6. Results of the study, entitled *The Effect of Marijuana on Seizure Activity in Man*, received June 15, 1980.

First, the 1972 consent form used by the Hospital for Sick Children does not include or provide the risks of any experimental procedure. If no experimental procedure was carried out, then I find it more than disturbing why there has been no response to my mother's letter, dated July 22, 1989, which you will find enclosed. It asks four questions:

- "1. Why was I not informed that you were going to keep him awake during this operation?
- "2. What happened to the photos that were taken during this operation?
- "3. Why was Terry given a false photo of his brain?
- "4. Did you not realize the after-effects in later years because of the way this operation was done?"

My mother ends this letter requesting, "I would like answers to these questions so I can put my mind to rest that at the time I did the best for him."

Today is February 14, 1992. Surely this doctor has been given more than sufficient time to reply. Obviously this doctor has a great deal to conceal. As such, he does not wish to disclose that he carried out an experimental procedure under the guise of medical treatment. Therefore, what a doctor carries out in an operating room and what is agreed on the consent form may not always be consistent and for the patient's best interest.

Second, I present two consent forms and related material in regard to the 1979 marijuana/epilepsy experiment. While being the volunteer subject at risk of this experiment, I cooperated in order to verify and substantiate the therapeutic potential of cannabis for the control of epilepsy. As such, it is questionable whether my attorney, Marlys Edwardh, received a misconception by a Dr Eugene LeBlanc that one of the psychoactive properties in cannabis, known as delta-9-tetrahydrocannabinol, in abbreviation delta-9-THC, also consisted of the anti-convulsant property known as cannabidiol, abbreviation CBD.

This misconception appears factual in Ms Edwardh's letter to the area director of legal aid, which you will find enclosed, dated October 6, 1977. On page 3, paragraph 5, and page 4, paragraph 1, she states she requested Dr Eugene LeBlanc of the Addiction Research Foundation to do a search in the field of marijuana and epilepsy. Ms Edwardh demonstrates her misconception where she states, "Dr LeBlanc canvassed the research into the anti-convulsant activity of cannabidiol and cannabinalol and there is a body of research which seems to indicate that one of the components of cannabis delta-9-THC has an anti-convulsant property which has been in some cases and could well be effective in assisting in the treatment of epilepsy."

One will notice that on the enclosed consent forms pertaining to this experiment lies a juxtaposition of delta-9-tetrahydrocannabinol and marijuana, thus giving a nebulous concept as to what drug is being administered. Yet I find myself being influenced under duress by a malicious doctor into signing, or threatened to never have any other opportunity to verify the potential of cannabis for the control of epilepsy.

Nowadays, realizing there is a great campaign for drug testing in the workplace, it is not difficult to surmise where the blood and urine samples were obtained in order to detect delta-9-THC in the human system. Therefore, this experiment, with its devious consent forms, had a purpose, but certainly not for the interest of myself or to evaluate the therapeutic potential of marijuana for the control of epilepsy.

Despite complaints to the College of Physicians and Surgeons of Ontario and appeals to the Health Disciplines Board, no impartial investigation was ever conducted into these three incidents of assault where fraud had been exercised involving medical experimentation. Yet I am to believe these procedures are a form of medical treatment.

Taking into consideration my personal experiences and the severe adverse effects, I would like to take the opportunity to recommend to this committee that section 8 be

amended to recognize the age of 18 as presumption of capacity rather than 16, unless it be for an emergency crisis situation, on the basis that at 16 years of age such person may be influenced to sign consent for a procedure that would not be in his or her interest.

1150

Subsection 10(3) should be accepted only if there is an office or a commission that an advocate or attorney is accountable to, to ensure that an explanation has not been put forth with deceit, coercion or misleading information. As history has proven, an advocate or attorney may think he or she is providing sufficient information, yet if it is discovered that an advocate or attorney has been used as a pawn to deceive a patient, there simply is no enforcement to ensure that a patient is not deceived by an ill-informed advocate or attorney at law. Certainly this would save expense of fraudulent research or non-therapeutic treatment.

It is further submitted that section 15 be included rather than excluded since there is no act when addressing: a procedure whose primary purpose is research; sterilization that is not medically necessary for the protection of the person's health; the removal of regenerative or non-regenerative tissue for implantation in another person's body. It can be recognized that in some situations research is needed in order to provide treatment as defined in this act. It is submitted that persons subject to risk of medical experimentation should have the right to a full, informed consent as to the risk involved and not be subject to cruel and unusual treatment when the procedure is not for the benefit of the subject at risk of medical research.

It is further submitted that section 24 be amended to provide a subsection to address the issue of invalid consent and that health practitioners be accountable for their actions and face liability when it is discovered they have obtained consent through deceit, misinformation, coercion or duress.

It is further submitted that subsection 32(2) be amended to instruct the Lieutenant Governor to compose the Consent and Capacity Review Board of at least 50% of members recognized as consumer/survivors of health care services in order to provide a board that can be recognized as fair and impartial.

It is submitted that subsection 46(2) be amended so that this act may apply in respect to previous treatment, whereas it would be applicable under the suggested annotations: that consent was obtained through fraudulent means; that treatment was not of therapeutic value; that consent was obtained without adhering to the guidelines as set out by the Medical Research Council of Canada.

In conclusion, it has been my personal experience that not all forms of consent to treatment were true in their words in regard to the actual treatment being provided. I can say this because I find myself in the same predicament as the Canadian army veterans who in 1949 were subject to lobotomy and left to suffer severe adverse effects; also, the CIA victims unwitting of brainwashing research experiments carried out by Dr Ian Cameron and the Allen Memorial Institute during the 1950s; and, lest we forget, the other abuses carried out by the clergy and other organizations which have been exposed over the past few years.

I am here to represent those who have been subject to risk of unwitting medical experimentation, from children to seniors. For this act to neglect the security and wellbeing of persons such as myself, no doubt the toll would be much greater for society to pay in the future. If Bill 109, the Consent to Treatment Act, is to be recognized as a contract, surely, such as in any formal contract, there exist safety codes, inspections, standards and performance. If this bill cannot comply with the abovementioned conditions, then consumers of health care services will not be provided the protection in order to secure good health and wellbeing.

I hope this information has been of interest and particular concern to the standing committee on administration of justice. I certainly hope my insight may expand your knowledge to the benefit of all mankind. Looking forward to your better judgement, may I thank you for this opportunity to address the broader issue related to this bill, and I welcome any further inquiry. This is my submission.

**The Chair:** Thank you. Questions and comments, Mr Poirier?

**Mr Poirier:** Thank you, Mr Parker. On page 4 and your proposed amendment "that section 8 be amended to recognize the age 18 as presumption of capacity, rather than 16," you will probably be shocked to know that since the beginning there has been almost a consensus to lower the age, and even remove the age, because of other situations that may not be the ones you have described. Obviously people have other reasons.

I think I can understand where you are coming from, as to why you want to suggest that; correct me if I am wrong, but unless I missed something, you are the first person to come forward who wants to increase it to 18, as opposed to eliminating it completely, so that people as young as maybe 12 and 10—not for the type of health services you are looking at, but for other types of health services.

Of course, it would be difficult to make a push, to say that for certain types of health services it is that age, or that other age, or start making a whole chart. That would probably be a nightmare to even try to think about it, but I just want to make you aware that you are really standing alone in that presumption, with all due respect.

You may want to compare, you may want to look at the Hansard as to why other people want to remove the age limit, because you are very much alone in this recommendation. I just thought you should be aware of this.

**Mr Parker:** That is accepted.

**Mr J. Wilson:** Thank you for your frankness. Am I to take it from your brief, your presentation, that when you made complaints to the College of Physicians and Surgeons, nothing was ever done to act on your complaints?

**Mr Parker:** I have provided the College of Physicians and Surgeons with information, for example, with the marijuana/epilepsy experiment, where two doctors give one story to the Ombudsman's office and then when I take the complaint further to the college there is a completely different story to the College of Physicians and Surgeons. Then when I take it back to the Ombudsman's office, they will not deal with it. When I take it to the Health Disciplines

Board the board makes its decision without even looking at the evidence. There are total inconsistencies with their information through the college and the Ombudsman's office. It is just totally neglected and they are not hired to—I mean, it is just one hell of a scandal, to say the least.

**Mr J. Wilson:** Thank you.

**Mr Parker:** When it comes to research experimentation, I have first-hand experience in this matter, sir, and it is abhorrent to see that the person who is subjected to the experimentation is not provided with a fair, impartial review by the college. There is no openness. You tend to see just basically one letter. There is no actual investigator, no policing power to act as advocate and to ensure protection of the consumer of health care services. That is my point.

**Mr Wessenger:** Mr Parker, it seems to me, if I am correct, that your major complaint here is that there was never any informed consent, never any proper information given either to yourself or your mother with respect to the procedures that were taken with respect to you, is that right?

**Mr Parker:** That is correct. They did it underhandedly, sneakily, it was just criminal—that is the word to use—it was extremely criminal what they pulled off, to my knowledge, for nothing more than psychiatric research in order to find ways and means to control psychiatric patients

through a surgical technique rather than medication. So they went ahead with a covert operation during the late 1960s and early 1970s, using mentally retarded people at Toronto General and epileptic children at the Hospital for Sick Children.

The adverse effects have been enormous, which I can obtain through records right across Ontario and the United States. You would think that when you go to a hospital and they say they are going to do something to you or whatever, they are going to be true and honest and get consent. In my experience, they have not been true and honest, and yet there is no impartial body besides the college to look into these matters, to provide protection in health care services.

**Mr Wessenger:** Yes, I think you have made your point very well. It is very important that informed consent be obtained. Thank you very much.

**The Chair:** Thank you, Mr Wessenger. Mr Parker, on behalf of the committee I would like to thank you for taking the time out this morning to come in and give your presentation. Thank you very much.

**Mr Parker:** Thank you.

**The Chair:** This committee stands recessed until 1:30 this afternoon.

The committee recessed at 1159.

## AFTERNOON SITTING

The committee resumed at 1337.

ONTARIO ASSOCIATION OF SPEECH-LANGUAGE  
PATHOLOGISTS AND AUDIOLOGISTS

**The Chair:** Our first presenter will be the Ontario Association of Speech-Language Pathologists and Audiologists. Good afternoon. Would you please identify yourselves for the record and then proceed.

**Mr Welland:** Good afternoon. My name is Rick Welland. My colleague is Sheila MacDonald. As you mentioned, we represent the Ontario Association of Speech-Language Pathologists and Audiologists, otherwise known as OSLA. We represent the 1,500 speech-language pathologists and audiologists in Ontario as well as persons with communication disorders.

Our presentation this afternoon is in regard to Bills 74, 108 and 109. Each of you should have a copy of our brief. It consists of a summary, detailed comments with our rationale, appendix A, which contains four case studies, and appendix B, which contains a chart that is an overview of the effects of cognitively based communication disorders on capacity. I will be presenting some of our summary comments, of which there are four main points. Sheila will then present a videotape of a couple of case studies. We will leave some time for questions.

The first question you may ask yourselves is, why are speech-language pathologists and audiologists interested in these three bills? Speech-language pathologists and audiologists are the professionals who assess and treat communicative disorders. Communication is intimately tied to the notions of consent to treatment, capacity and advocacy.

I draw your attention to Bill 108, section 46. There is a quote in there concerning incapacity of personal care. The capacity definition in the Consent to Treatment Act is worded very similarly. The part I have excerpted says, "if the person is not able to understand information that is relevant to making a decision," and so on. I highlight the word "understand" because it is certainly one of the integral acts of communicating. That passage goes on to talk about appreciating consequences of decisions. That is certainly another facet that is critical to the definition of capacity or incapacity and it is certainly a cognitive as well as a communicative act.

Bill 74, clause 7(1)(b), talks about the role of advocates and says that one of the their roles is "to help vulnerable persons to express and act on their wishes, ascertain and exercise their rights" and "speak on their own behalf." Certainly expressing one's wishes and speaking for one's self are important concepts for how vulnerable persons are expected to assist advocates in performing their duties. These are also integral acts of communication. Ascertaining one's rights and making decisions again are cognitive and communicative acts.

To give you some kind of background of what I am talking about by cognition and why we are interested in that and how it affects capacity, cognition affects communication, which in turn affects capacity, which in turn affects

how the person functions in our society. In our role as advocates for our patients' rights we are very much concerned with capacity.

Let me give you a very brief overview of what cognition entails. These are the main processes that come under the cognition umbrella, so to speak: attention, concentration, memory, creative thinking or problem-solving, and reasoning or judgement. Those are the things we mean when we are talking about cognition.

I would like to now address the four main points from our summary that we would like to highlight for you this afternoon.

The first point is that cognitive and/or communication disorders are very much different from mental or physical disabilities, which is part of the current definition of a vulnerable person. Cognitively based communication disorders that might result from something like a closed-head injury, some strokes, brain tumours and dementias are not the same as emotional or psychiatric disorders, which is the usual thing the layperson would infer from the word "mental." A person with a purely physical disability, while otherwise challenged, can still communicate, make decisions, and in many cases, act upon those decisions. We believe that cognitive and/or communication disorders are complex enough and distinctive enough to warrant specific reference in the definition of a vulnerable person.

Second, many people with communication disorders, perhaps due to a neurological condition such as a stroke, cerebral palsy or Lou Gehrig's disease, have difficulty speaking clearly enough to be understood by others. Still others who may have had a closed-head injury or another kind of stroke or a brain tumour have difficulty showing that they understand what is being said. For many, simply asking them, "Do you understand the information being given to you?" does not give them the opportunity to perform within their capabilities. We suggest that references within the acts that talk about knowing, understanding or appreciating information be prefaced by a term like "demonstrate." How the person is asked to demonstrate understanding would of course vary with the skills of the vulnerable person and his or her deficits.

Our third point entails the assessment of capacity. It is our understanding that a capacity determination is a complex process. We believe it should be conducted by several professionals who each contribute their own distinctive perspective and expertise to the process. For example, a psychiatrist would approach a capacity determination in a very much different way from the way a psychologist would approach a capacity determination, while the speech-language pathologist would approach a capacity determination in again a different way—that is, from the viewpoint of communication and cognition and how they affect capacity. It should be self-evident that where communication is an issue the speech-language pathologist and/or the audiologist are the ones who should be consulted.

I do not believe we can assume that other professionals know to consult the professional with the most expertise in

addressing the special needs of the person being addressed. We believe the legislation needs to state more explicitly the interdisciplinary nature of capacity determination. Also, where advocates are concerned, the legislation needs to be explicit regarding how this person's special needs become determined. We believe it should be explicitly stated that where the special needs are unclear or unknown, an assessment or perhaps assessments should be conducted by the professional or professionals who have the most expertise in addressing those special needs.

Our final point concerns the use of existing advocates. We would like to remind the government that there are already advocates working on behalf of some vulnerable persons. Specifically, people with cognitive and/or communication disorders have historically had speech-language pathologists and audiologists who, as part of their role, act as advocates for their clients. Often we are the ones who best understand the individual's strengths and areas of weakness. We are often also the ones who know how to provide the most opportunity for those persons to demonstrate their maximum independence in communicating. Oftentimes we are also called upon to act as a translator, sometimes for the person's behaviour such that other people understand why the person is acting in that way, sometimes to interpret specifically what the communicatively impaired person is saying, and sometimes to interpret what others are saying to that person.

Speech-language pathologists and audiologists have the expertise and are certainly willing to act as educators of other advocates. But we ask if it is in the public's best interests to replace existing, very well-trained advocates with new untrained advocates. This is especially for individuals with communication disorders. Surely hiring and training new advocates would be more costly than utilizing the unique skills of those professionals who are already acting as advocates.

I would like to turn the presentation over to Sheila MacDonald, who will show you a videotape.

**Ms MacDonald:** I will be moving back and forth between the video so I am going to put this microphone on and hope you can hear me. Can you hear me if I speak like this?

Interjections.

**Ms MacDonald:** I am not Hansard-literate.

Interjection.

**The Chair:** Possibly I could suggest that the members over here come to this side so they can see better.

1350

**Ms MacDonald:** That might be a good idea. What I am going to show you today are three people, all of whom have different issues with regard to cognition, communication and capacity. All three have been involved in some sort of accident that caused a head injury. All three have very different abilities and require different advocates and different interpretations of, and assistance with, informed consent etc. These three cases should highlight for you some of the points that Rick just made.

The first person is someone who was involved in a motor vehicle accident. She is paralysed completely. She is

unable to speak in the normal way. She uses her eyes to communicate. She lifts her eyes up for "Yes" and down for "No." Using this system I am able to learn from her what her needs are and to advocate on her behalf. I hope this video will work.

[Audio-visual presentation]

**Ms MacDonald:** She is spelling to me. I am moving my hand along a letterboard. She lifts her eyes up when I get to the right letter. I have asked her, "What things do you need help with in the evening that you are not getting enough help with right now?" This woman demonstrates for us nicely the point that a person can, despite the fact that they have physical difficulty, express a wish, given the appropriate assistance.

This woman is able to understand and appreciate the consequences of her decisions. She just needs some assistance in expressing those decisions. Any advocate would have to be trained in the appropriate questioning in order to get at what it is she needs.

I might add that she spent some time to convey things to me, such as the fact that she was allergic to penicillin. I had to then convey that to the staff, but first advocate on her behalf the fact that she was cognitively intact in order to be able to say that, because there was a bit of a bias that someone with a head injury might not be cognitively intact.

Also, we had to assist her with informed consent decisions as well, in that she was moved on to another hospital and she had to be given a choice about whether she would like to move on to that hospital or not. Plus there were medical procedures where her consent was needed and I, as a speech-language pathologist, interpreted for her at the time what her choice was in that.

The next person I would like to show you is a gentleman who was involved in an accident and sustained a head injury. He, unlike this woman, is able to communicate very quickly and with good speech, but his thinking skills are impaired. He may look good initially at the bedside but not be able to make an informed judgement or appreciate the consequences of a decision.

Allow me a few moments while I eject this and move on to the next.

This man was on an orthopaedic floor. Initially he was not felt to have a head injury. He would probably have been discharged to a orthopaedic hospital, with everyone thinking that he was thinking just fine, unless the head injury team had not gone in to learn otherwise. So you get the point that he is sounding all right.

Now I have to turn the volume down and fast forward. Bear with me a moment because the contrast is worth it in the end.

In the next part you are going to see where he is not thinking so clearly. We are almost there. Initially you will hear him sounding quite clear and answering simple questions very well. As the questions get harder he will break down. Listen carefully.

I think we will stop there.

1400

**Mr Winner:** I wanted it to go on.

**Ms MacDonald:** I know. You get hooked on it.

To conclude, I showed you today two different cases: one who had a communication impairment, one who had a cognitively based communication impairment, not a physical impairment, and neither of them had a mental disorder. This is our point today.

To reiterate and to conclude before questions, the three things I hope these videos helped to elaborate on—the three points that Rick has already made very nicely—are that persons with cognitive and communication disorders are different in terms of their needs from those with mental or physical disabilities, that an individual must demonstrate understanding or appreciation before one can assume that there is adequate understanding, and that an assessment and determination of cognitive competency, particularly among the communicatively impaired and the cognitively impaired, is a complex endeavour that requires special expertise and a team approach.

With that I will pass on for questions.

**Mr Poirier:** It is not so much a question as appreciation for bringing forward these distinctions that obviously can get caught in the cracks. They are very important points that I am sure will be noted by legal counsel to make sure that whatever is brought forward is respectful of that, and I fully support that. Thank you for bringing it forward.

**Mr J. Wilson:** Thank you to the presenters. I thought the video was a good idea. In the latter part though, in all seriousness, although I do not doubt the diagnosis that there was a cognitive dysfunction there, he did have good reasoning for his choices. Does he get points for that?

**Ms MacDonald:** Yes.

**Mr J. Wilson:** My mother is a special ed teacher and she is always putting me through these things, or at least when I was young, and I never used to—

**Ms MacDonald:** Did you have any difficulty keeping up with them? I am teasing.

**Mr J. Wilson:** You have been watching the hearings too much.

**Ms MacDonald:** Mr Wilson, you have brought up a very important point: that no single test can be all-conclusive. In fact there were some questions where he reasoned well. So no single test is conclusive. On an earlier test, which I did not get to show you so it is not fair, he did not know how old he was. I think that one who is to do his own financial accounts etc, should at least know his age and the year.

**Mr J. Wilson:** Sure. Just so that I have the general purpose of this, what you are saying is that speech-language pathologists do advocacy now—that is clear from the video—and that you must be included in any future advocacy systems, it is about that simple, or advocates would have to have a high degree of training such as yourselves. What do you think of the latter part?

**Ms MacDonald:** Yes. I think that any person with a cognitive or communication disorder should have a team of people to assess, first of all, to help to maximize that person's skills and his or her ability in getting across his needs and choices, and that where there is a cognitive or

communication disorder, a speech pathologist would be very helpful in at least training the advocate, if not already advocating on the person's behalf.

Sometimes you are already going to advocate. If this person tells me that she is allergic to penicillin, I had better move on that right away and not wait for an advocate to come into the hospital and fill out forms with us. But on the other hand, there are some things where it would go beyond the interaction of the speech pathologist and an advocate would be better—for example, maybe to go to court with the person or whatever.

**Mr J. Wilson:** Okay. I appreciate that. Thank you for the clarification.

**Mr Poirier:** A technical question. When you were with that woman, what you find out about what she needs, what she wants, does not want, allergic to penicillin, for example, I presume that all goes in a dossier. Is that dossier available to other care givers, for them not to have to repeat the same tests again every time?

**Ms MacDonald:** Yes. Good point. In fact, I sent this video on to the next rehabilitation hospital. That is one example, and there is always a medical chart in this person's case. Now if the person were in the community, I think we need to get better at having those sorts of dossiers moving along with the person in the community.

**Mr Poirier:** How do you handle the confidentiality of some of the information that you get out of that? Is that a problem?

**Ms MacDonald:** Again, it is very tricky in determining whether the person is able to give us consent to send on the information, to release the information. So if they are able to give us consent, we have to ask them. If they are not able to give us consent, then we as a team help the family, or whoever problem-solves, about who is going to be that person's advocate, and then we get their consent.

**Mr Poirier:** Because I presume with a person in that type of state, just about every care giver at every level would have to consult that dossier, because not everyone has your technical skills to be able to search for and ask the right questions and proceed in the right fashion to get to the right answer as soon as possible.

**Ms MacDonald:** Exactly, yes.

**Mr Poirier:** So just about anybody from the RNA to the RN to the doctor to everybody, right?

**Ms MacDonald:** Yes. There is constant training that we all do with all the staff in order to reach that level of understanding.

I was just going to add one more thing. One of the reasons I, as an individual, am excited about this legislation, all three acts, is that I think finally it is going to create a community awareness of these needs so that it will be easier to argue that all staff must attend to these people's needs.

**Mr Poirier:** One last point. Will the confidentiality of all this be enhanced or harmed or affected by the new acts? The confidentiality of what you may find or learn from your interviews.

**Ms MacDonald:** That is a good question. Do you want to take that one?

**Mr Poirier:** It is a test, by the way. It is a test.

**Ms MacDonald:** I think it would be enhanced, because first of all you would have to ask the person having been deemed cognitively intact but communicatively impaired and, second, it could be faster to make a decision of temporary incompetency to get on with things if information needs to be sent but you want to declare that person temporarily unable to give you consent.

**Mr Poirier:** Temporarily.

**Ms MacDonald:** Yes.

**Mr Poirier:** Tell me about it.

**Ms MacDonald:** In the hospital situation we are all very frustrated in working with the old acts, where you had to wait until you got someone declared mentally incompetent before you could proceed with anything. Then once they were declared mentally incompetent, three months later when they are able to make their own decisions they are still finding themselves having to fill out forms to get socks at Zellers or whatever.

**Mr Malkowski:** I found your presentation fascinating and I was very impressed with it.

I would like to ask you two brief questions. First, would the term "neurological disability" cover the kinds of things you are talking about, the ability to understand, to reason? Would that solve that problem?

**Mr Welland:** Not in all cases. Certainly there are many neurological conditions where the person's ability to reason and think are not affected. I can think of many types of individuals who have had a stroke. People who have Lou Gehrig's disease, for example, are not so affected but people with closed head injury in most cases are affected in that way. Some people with another type of stroke, stroke on the right side of the brain, in many cases are affected in their thinking skills and other kinds of neurologic conditions such as that.

1410

**Mr Malkowski:** Okay. The second question: Deaf people, or people who are hard of hearing, have already tried to perhaps get sign language or oral interpreter services at the hospitals, and often their experience has been one of frustration because the medical profession refuses to recognize interpreter services during assessments. Have you had the same experience with the medical profession in terms of accepting the speech-language pathologists acting as interpreters? Communication is so important to the assessment. What kinds of experience have you had with the medical profession?

**Ms MacDonald:** I have had just two times when I have been working with someone who has a hearing impairment and needs an interpreter. I think the best way to describe the situation was that it was clumsy, in that there was a time lag before we could get a good interpreter there and before everyone realized the necessity of having a good interpreter there at all times. I agree with you that we should make that process a lot more easy to access, but I

have never had a physician deny the person a right to an interpreter. I would be horrified if that happened.

**Mr Welland:** Further to that point: There are many examples, and this is not with the individual who may be deaf but hard of hearing. This certainly comes into play with the elderly individual who has been hospitalized. In many cases it is quite difficult to get a hearing assessment done prior to some of the other assessments being done. The consequence of that is, in a number of cases, and unfortunately far too many, the assumption is made that the person does poorly on the testing because he is dementing, when in reality he has hearing loss.

**Mr Winninger:** I got a lot out of your presentation. I note that the third point of your summary suggests that assessments of professionals come from the most competent professional to address their special needs. I want to make sure that you are aware of section 50 of Bill 108, which provides that, in a validation of a power of attorney for the person, the wishes of the person can be respected. They might name two assessors in the power of attorney in the event that they become incapable, and that might include a speech pathologist.

I would also suggest that if there are no preferences indicated in the power of attorney, the second part of section 50 provides that the assessment will be done not only by a physician but another assessor as well. I would hope that that particular section will serve to address your concern that the communication and cognitive disorders will be ascertained.

**Mr Welland:** I think the attempt is certainly clearly there. However, it is our experience that in many cases the communication disorder is not even recognized by, for example, the physician, who may be the person who first has contact with the individual. In that case there would be no guarantee that the speech-language pathologist or the audiologist would be consulted. I am assuming you are talking about the power of attorney being predetermined. Is that the one you are referring to?

**Mr Winninger:** I am referring to when a power of attorney is validated. The power of attorney may or may not state a preference for assessors as to capacity. That is section 50.

**Mr Welland:** Right.

**Mr Winninger:** How would you get around your concern that a physician may not be sensitive to the need for an assessor as to communication and cognitive disorders?

**Ms MacDonald:** You make it mandatory that any person be assessed by a team of individuals and you give the team of individuals the right to make statements on that person's behalf in court or in any serious situation rather than having, as it is right now, a physician's signature or two physicians' signatures.

Sometimes a team might involve a nurse who sees the person for 24 hours a day and knows that John Smith wanders at night, although he sounds clear in the daytime. Sometimes the best assessor might be a psychiatrist and a nurse. Sometimes the best assessor might be a speech pathologist and a social worker where there is a question of

whether it is depression or an unwillingness to talk or an inability to talk.

We have to be flexible and say that it has to be a team, and for any type of disorder that team should be, in a sense, driven by the individual's needs rather than by a predetermined formula.

**The Chair:** Ms MacDonald and Mr Welland, on behalf of the committee I would like to thank you for taking the time out this afternoon and coming here to give your presentation.

**Mr Welland:** Thank you very much.

ADULT PROTECTIVE SERVICES  
ASSOCIATION OF ONTARIO

**The Chair:** I would like to call forward our next witnesses, Gianni Corini and Steve Tennant. Good afternoon. As soon as you are comfortable, could you please identify yourselves for the record and then please proceed.

**Mr Corini:** Good afternoon. My name is Gianni Corini. I have been an APS worker since 1978 and a member of the Adult Protective Services Association of Ontario since its inception. I represented the association on substitute decision-making for mentally incompetent persons and more recently on the Ontario Advocacy Coalition. I am also the past chairperson of the Adult Protective Services Association of Ontario. We are here representing the association today. I presently act as a consultant to the association. My colleague, Steve Tennant, is also an APSW and he will be introducing himself.

**Mr Tennant:** Good afternoon on this day of hearts. Happy Valentine's Day. I am Steve Tennant. I live in lovely downtown Perth, Ontario. I am also an APSW and have been one for 10 years. I have worked in the field supporting individuals with developmental handicaps for the past 18 years in various areas of the province.

**Mr Corini:** As a way of opening, I would like to express the APS workers' appreciation to the committee for the opportunity given today to represent the view of APSWs across the province on what we consider literally a vital piece of legislation, Bill 74. At the outset, APSAO would like to express its support to the introduction of advocacy legislation and today we welcome the opportunity to address some of the concerns we have in respect of the introduction of Bill 74. Because of time constraints today, we will highlight aspects of the submission that is before you and also a memorandum that was later introduced to the submission.

We feel that our attention should be concentrated on some aspects of the bill that we feel are particularly important.

**Mr Tennant:** By way of background, the Adult Protective Services Association of Ontario, more commonly APSAO, is a non-profit provincial body representing approximately 175 adult protective services workers in Ontario.

The adult protective services program was launched in 1974 by the Conservative government following public concern about individuals with adult mental handicaps living independently in the community without sufficient support. There were also concerns that guardianship would

be overutilized for these individuals if they did not have advocates to protect their interests.

The provincial guidelines developed by the ministry, which stress advocacy as an important function of these workers, have never been fully addressed since APSWs are unable to properly exercise their advocacy function due to the conflict of interest of being sponsored by the ministry, which is often the author of their clients' difficulties.

1420

**Mr Corini:** The Adult Protective Services Association is very pleased that the government has undertaken to introduce this important act to protect the rights of disadvantaged people. It contains several very important provisions concerning advocates' access to records, their clients, and facilities which correct long-standing difficulties advocates often face in seeking redress for their clients.

The basic philosophy of the bill is also sound in that it promotes self-advocacy and stresses a community development approach in the provision of advocacy services. It is a culturally sensitive bill which empowers people who have been disadvantaged by charitable and service-oriented approaches to their problems which have tended to promote a patronizing atmosphere, thereby undermining their efforts to achieve true independence.

This association strongly supports the government's decision to ensure consumer control of the Advocacy Commission and we support an open-ended definition of who will require advocacy services. Too often new agencies and services have tended to exclude people. This act is drafted in a way which includes people. It is a step which, in our view, must be taken.

We feel that required additions and modifications are necessary to the bill and we would like to stress your attention on the fact that the Advocacy Act does not rationalize the existing advocacy system.

There are several areas where the bill falls short of expectations. It does not take a comprehensive approach to rationalizing the existing advocacy system. The psychiatric patient advocate program currently housed in the Ministry of Health will transfer to the new Advocacy Commission, thereby ending a long-standing conflict of interest for the advocates employed by that program. But the bill leaves adult protective services workers, who also have an advocacy mandate under provincial guidelines, mired within the Ministry of Community and Social Services which does not support their advocacy efforts. This creates a basic inequity between psychiatric survivors in facilities and those with developmental disabilities in group homes. One group can expect to have an independent advocate who can act vigorously for them, whereas the other will have to rely on an advocate whose salary is paid by the same ministry which pays the salaries of group home staff.

Similarly, the act does not deal with the office of child and family services advocacy, also housed within the Ministry of Community and Social Services. This office deals with children and adults, and its advocates are not free to act without conflict of interest. There is some concern that advocates in this office see their role as one of listening and mediation rather than vigorous advocacy because of

conflict of interest. This is an issue that should have been addressed by the Advocacy Act and was not.

We are therefore recommending that the act include provisions which transfer the adult protective services system from the Ministry of Community and Social Services, intact, to the—originally we said “to the new Advocacy Commission,” but we feel at this point that perhaps a parallel program with the office for disabled individuals can also be sufficient.

We further recommend that the advocates in the office of child and family services advocacy come under the auspices of the commission until such time as the government establishes an independent and comprehensive advocacy system for children.

**Mr Tennant:** Moving down to (c), the bill also has no provision dealing with emergency entry for advocates who have reasonable grounds to believe that someone is being harmed or is in imminent danger. An example might be an advocate approaching a boarding home where the beating of a resident is in progress. It is likely that as soon as the advocate leaves to obtain a warrant and alert the police, the beating will resume. As we saw in the Cedar Glen case, beatings like this can result in death. The new act requires a section dealing with emergency entry.

Moving to (e), the selection process for representatives for the commission does not ensure that those who are the most vulnerable in our society, precisely because they are non-verbal, comatose or otherwise unable to express their wishes, will have an adequate representation on the commission.

Individuals who carry various diagnostic or social labels who have formed organizations to address their needs are very capable of advancing their particular interests. However, those who are not capable of forming or joining organizations are often those who have the most to lose, and they are also often the individuals most likely to be victims of abuse or neglect.

We are recommending that the minister appoint at least two representatives to the commission with a demonstrated track record in acting effectively on behalf of severely disabled persons who are unable to indicate their wishes because of severe cognitive disorders, severe brain injuries, perhaps because of drug or alcohol abuse, being comatose, or for any other reason.

There is an oft-repeated phrase that states that society is judged on the support provided to the least able. Given that Ontario is taking on the task of preparing this act, let's make sure we are able to hear from those who are least able to be represented.

Moving on to (f), the act does not provide for a minimum number of regional offices to ensure that advocates are as available to people in Kapuskasing as they are to those in Metro Toronto. We recommend that the act include a minimum number of regional offices. Ontario is a large place and it is not just made up of urban areas. People do not have transportation availability, so the availability of the advocates across our province is something that is very important and the destruction of that is being seen right now in the APS program.

**Mr Corini:** One of the aspects in doing our job and in our experience is that—and we have seen it with the adult protective service worker program when we have done quite a bit of systemic advocacy—an act that empowers advocates and their clients but does not demand responses from government can be very ineffective. Even the best advocate can be thwarted where there is no duty placed upon government and its agencies and commissions to respond appropriately where an advocate raises concerns on a client's behalf.

As an example, APSAO has been, as I have just said, for several months raising systemic concerns about the confidentiality of clients' records held by agencies funded by the Ministry of Community and Social Services. The ministry, including the minister's office, has been exceedingly lax in responding to these very basic concerns. We therefore recommend a provision in the act which requires government to respond to concerns raised by the commission within a specified period of time.

**Mr Tennant:** Section 7 of the act discusses the functions of the commission. Nowhere does it say that advocates will promote the integration of disadvantaged people into the mainstream of community life. This is an important point. The act should list as one of the functions of the commission “to assist vulnerable persons to fully integrate into all aspects of community life.”

There is also no function which specifically says that advocates will take action to protect their clients from abuse and neglect. In light of the institutional abuses which have been seen over the past several years, this needs to be stated. The act should include a section which says that advocates will help to protect individuals from abuse and neglect.

The definition of “vulnerable person” in section 2 also fails to protect the most vulnerable people in Ontario. It states that a vulnerable person is someone who has difficulty expressing his or her wishes. It does not include those who are unable to express their wishes. It should include the wording, “those who have difficulty or are unable to express their wishes.”

1430

**Mr Corini:** One of the other things we did not find in the act is provision for appropriate evaluation of community-based advocacy efforts by the commission. Tied to this is the issue of funding. The commission may fund a community advocacy group, but there is no provision that spells out when the commission might consider defunding a group, including a process for doing so. We recommend that a section be added which allows the commission to defund an agency, group or organization providing advocacy services which includes the process and condition under which this may occur. Advocacy services must be at least as accountable as other service providers.

There is also no duty on the minister to act upon the annual report. Subsection 11(2) has the minister tabling the commission's annual report in the Legislature. It places no duty upon the minister to pursue unresolved concerns. Many annual reports are tabled in the Legislature and then forgotten. It would be useful to consider placing a duty on

the minister to act as the commission's advocate with government by placing a duty upon her or him to pursue unresolved issues which pertain to government and which remain unresolved from the commission's annual report.

There is also no provision for research. I believe that Ontario is probably breaking ground in terms of advocacy legislation, and because of that it would be extremely important for Canada, not just for Ontario, perhaps even in the international community, that the provision for research be entrenched in the legislation. Since Ontario is on the leading edge in providing advocacy services, it seems reasonable that the act should speak to the need for research in this area and make comprehensive research possible, subject to certain safeguards. We recommend, therefore, that a provision be added to the act which encourages research and sets out the conditions which must be observed in order for it to occur.

There is also a potential for abandonment in a coercive situation. If a vulnerable person indicates that he or she does not want an advocate to stay, subsection 21(3) places an obligation upon an advocate to leave. While this is important in the protection of the client's right to self-determination, there is a danger that the client is dismissing the advocate because of coercion. This section does not adequately take into account the symptoms associated with the Stockholm syndrome, in which individuals who have been abused or battered sometimes identify so strongly with the perpetrator in order to survive that a hostage mentality develops and they act according to their abuser's wishes. It also does not take into account the possibility that an individual is being threatened or coerced to get rid of the advocate. More thought should be given to this section so that the act does not abandon the individual in this situation.

We have seen that situation clearly in Cedar Glen when one of the residents was acting as an enforcer for the owner and in fact was the one who was doing most of the beating of some of the residents. He obviously was acting under the coercion and threat of the owner. We have seen that kind of situation as being a very real one in many situations in group homes and places where there is coercion and no possibility for people to find out or go in and advocate.

**Mr Tennant:** Subsection 24(3) drives a wedge between the advocate and client and infantilizes the client. It makes the client captive to the wishes of his or her doctor, thereby undermining the client's right of access to information and self-determination. Clients should have the right to see their files and correct them if necessary. Clauses 24(3)(a) and (b) should be deleted.

Section 25(1) gives access to records of a person "living or dead" held by a facility. This section should be amended to include records held by the coroner's office. The schedule, section 17, at the back of the act lists a number of facilities governed by various acts to which advocates should have access. Several acts are missing. They include the Education Act, the Health Disciplines Act, the health services consent act, the Public Health Act, the Substitute Decisions Act, the Coroners Act, the Ontario Human Rights Code, the Ombudsman Act, the Legal Aid Act, the Public Trustee Act, the Family Benefits Act, the General Welfare Assistance Act, the Homemakers and Nurses Ser-

vices Act, the Indian Welfare Services Act, the Vocational Rehabilitation Services Act and the Health Facilities Special Orders Act. Access may be necessary to records held under the authority of any of these acts if effective systemic advocacy is to occur.

**Mr Corini:** We just circulated a memorandum that is supposed to be an addendum to our submission to this committee. APSAO has noted that subsection 1(1) of Bill 108, An Act to provide for the making of Decisions on behalf of Adults concerning the Management of their Property and concerning their Personal Care, defines the term "advocate." Clause 16(5)(a) sets out the duties of an advocate, which are to meet promptly with the person to whom the certificate of incapacity relates and to notify him or her of the certificate, explaining its significance and explaining the person's right to refuse and, finally, to ask the person whether he or she wishes to refuse it.

This association is of the strong belief that an act administered by one ministry, in this case the Ministry of the Attorney General, cannot dictate what employees of a commission of another ministry, the Ministry of Citizenship, must do. The role set out for advocates in clause 16(5)(a) of Bill 108 is not, in fact, an advocacy role but could easily be performed by a clerk. It is the role of an advocate to align with the client and act on his or her instructions, not as an emissary of a government or quasi-government agency.

This association is therefore recommending that the rights adviser role be funded by the Ministry of the Attorney General and administered through the legal aid system. The original funds voted by the cabinet for the Advocacy Commission must be used for advocacy, and there should be no encroachment upon these funds by the Ministry of the Attorney General for the purpose of funding rights advisers.

Clause 7(1)(d) should be deleted from Bill 74, An Act respecting the Provision of Advocacy Services to Vulnerable Persons, since it takes control of what advocacy services are to be provided away from the Advocacy Commission and places these duties in the hands of another ministry, which wishes to create advocacy functions without providing the financial resources to do so.

This association notes that Bill 109 has the same problem. Subsection 1(1) of An Act respecting Consent to Treatment also defines the term "advocate." Subsections 10 (1) and (2) demands that an advocate meet with a person concerning a finding of incapacity by a health practitioner. It is obvious to this association that the rights adviser duties in both Bills 109 and 108 are thinly veiled attempts to totally undermine the real duties of an advocate as set out by the Advocacy Act. We are asking the committee to propose amendments to all three acts which will place rights adviser duties within the purview of the legal aid system, not the Advocacy Commission.

Thank you very much for your time.

**Mr Sterling:** This is the third group that we have heard from the Adult Protective Service Association. Your briefs have been basically similar. In terms of the daily lives of the 177 workers, how much time is spent on advocacy and how much is spent on other matters?

**Mr Corini:** It varies. It depends very much on the area where the advocate operates and where he is providing services. It also depends very much on the sponsoring agency, how much freedom that sponsoring agency will allow the APSAO worker to perform advocacy duties. It would depend, of course, on the needs of the people to whom the advocacy duties and responsibilities are applied, specific individuals.

We have had some data collected in the past in terms of how much time is dedicated, but I would say it is not consistent throughout the province. There are many variables, as I said, according to many different situations. I think we can say that adult protective services workers, taking into consideration all I have said, are providing between 20% and 40% of the total time for advocacy.

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**Mr Tennant:** If I could add to that, as Gianni said, one of the variables in regard to that is availability of services for that individual who is already in that area. In a time when we are looking at financial constraints, services are having a great many problems providing for the people in their areas. In light of that, there is an increasing need for advocacy.

The other thing we have to remember is that the clientele we are working with quite often have not had the opportunity to speak and act on their own behalf, and that is a learning experience, where, say, maybe someone has been living with mom and dad for a lot of his life. Suddenly either mom or dad dies and a medical crisis comes into effect. All of a sudden this person is expected to make a big life decision—where does he want to live next? The expectation of that is a little unreal. Therefore, involvement of APSWs in developing a rapport with that individual prior to these crises is crucial to that individual having the trust in an advocate, which is certainly something that is crucial in interaction between an advocate and an individual, that trust in knowing that what that person is and the variables that person is presenting to him are things he can believe in and make his choices on.

**Mr Sterling:** The next is just a comment. In part (g) of your recommendations, page 5, you say there should be a duty placed on the government to respond. I think there is a duty on any responsible government to respond; whether or not it chooses to respond is the question. I, as a member of the provincial Parliament, do not have the right to demand a minister in the Legislature to respond to a question that I might ask him or her on the floor of the House. Any other citizen in the province does not have the right to force a minister or the government to respond. Do you suggest the commission should have a power that nobody else has?

**Mr Corini:** I think that is a consideration, because otherwise systemic advocacy will be grossly undermined, in my opinion. We see today quite a few problems with the Office of the Ombudsman and sometimes with the Human Rights Commission when they make a recommendation to government during an investigation. Again, this is a new act and we are breaking new ground. I know it is also a new kind of concept and philosophy, and therefore I think

that in order for us to believe that the Advocacy Commission will have the power to then influence systemic changes, there should be some responsibility on government to respond to some of the commission's findings when it has been ascertained that there is some lack of services in certain areas. If there is no provision for government to respond, then I would think many of the changes the commission may be recommending would just be left unattended. I think that is an area that should be addressed in some way.

**Mr Sterling:** I just find the suggestion strange to our system of government. I am not getting away from the point that any responsible government should respond and that it is subject to the political consequences of not responding. It is difficult sometimes to get a response, and sometimes, quite frankly, as a government it is difficult to respond because it is limited in its resources.

I have a great deal of concern about the Advocacy Commission. As someone who is concerned about accountability within the system and to the people of Ontario, I am very much concerned about placing an Advocacy Commission out there on an island in the middle of the ocean, not being really accountable to anyone. There is nothing within the Advocacy Act which really allows a disgruntled client or an opponent of the advocate to complain to anyone what an advocate might or might not have done in representing the client. Would you care to comment on that?

**Mr Corini:** Yes. I think that is a valid point and that is something that, in fact, we have been stressing in terms of—for instance, in certain areas of the province the APSW program has been under attack. That is why we said that there should be some duty on government to respond, because we never had any responses from our concern. We have been fighting to have those kinds of responses, and we are still waiting after years of concern expressed and not responded to.

One of the things we found—our program is under extreme pressure from local areas—is that we are an amalgamation of services. For instance, in the north in Sault Ste Marie and Thunder Bay, service is amalgamated. That is, all social services in that specific area were under one umbrella organization, and the APSW program was also placed under that big umbrella organization. Therefore, if a client had some dissatisfaction about the services provided he did not have anywhere else to go because the services were provided by just one global entity.

We certainly are sensitive to this area and we feel there should be a system to address the concern of individuals who may have their needs not addressed or not met by an advocate, therefore being able to access some alternative services either on a voluntary basis, which the act provides, or some other ways. We agree with—

**Mr Sterling:** Can I just ask one final question?

**The Chair:** Very quickly.

**Mr Sterling:** The Ombudsman, the information and privacy commissioner, the election expenses officer, the chief returning officer of the electoral system, all report to the Legislative Assembly directly. Do you think it would not be more appropriate that the Advocacy Commission

would report directly to the Legislative Assembly and not to a minister of the crown?

**Mr Corini:** I can respond by just making a comment that the more distance there is between the commission and government the better it is in terms of its independence.

**Mr White:** Thank you, Mr Tennant and Mr Corini. I have for many years worked with adult protective services workers. In my last employ there were two across the hallway from me at Durham region, and I am very familiar with their role and your role. Frankly, I am amazed at what excellent advocates you are. Certainly the women whom I have worked with have been excellent, given the circumstances they are in. As you mentioned, when you are funded by the same ministry you are under constant pressures that are subtle sometimes, sometimes not. Even though you are funded through a different agency, through a different source, those pressures still exist. That point you make is a very important and significant one.

It only makes sense that there is that separation. As you were saying, Citizenship is at least one step removed from the front-line ministries. But I understand that one of your principal concerns with the Advocacy Commission is what you outline here: It does not rationalize the existing advocacy system or recognize the tremendous role you have had in the front lines in terms of advocacy. I think your talk and your points have been very succinct, very pointed, and very emblematic of the fact that you are in the front lines in that area. Does the act itself preclude your being involved, or is that a policy decision?

**Mr Tennant:** We feel at this point it pretty clearly does, and that the APSW program is not being transferred under this act as the patient advocate program is.

**Mr White:** It is not. But that is a policy issue, not an issue about the act, though, is it not? That could happen in the future.

**Mr Tennant:** Lots of things could happen. One of the basic problems of the APSW program to date is its lack of solidarity in legislation. The APS program is not legislated. As you are saying, yes, it could be. It could have been for the last 15 years that the APSW program has been around, and in fact what we have seen is a program that is being taken apart effectively in the province, not a program that has been given strength. For people who are not aware, in Sudbury and Manitoulin Island the area office for the Ministry of Community and Social Services has seen fit to no longer have APSWs in that area. So, in effect, people with developmental handicaps in that area no longer have an advocate. Here we are with a program that is supposed to be provincial in scope but, in fact, area offices are doing as they see fit.

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If I could take a moment of your time, on November 6, 1991, I wrote a letter to Elaine Ziemba in regard to this, and it was in response to her being at a conference of APSWs and comments that she made:

"Listening to your comments only reinforced my feelings of the need, both rationally and fiscally, for the APSW program to be included in the Advocacy Act.

"How can 175 to 200 advocates you're proposing even scratch the surface of the 300,000 you stated may qualify for these supports?"

"Given the expectations being placed on the new system from the health sector alone, expecting informed consent, how will these proposed advocates ever keep up?"

"Impossible! Doomed for failure!"

"For 15 years the APS program has been attempting to support the 2% of the population of Ontario recognized as developmentally handicapped, approximately 54,000 people. With 170 workers in the province, there are still long waiting lists for APS support.

"By transferring the APSW program to be included under the Advocacy Commission, you will have approximately doubled your number of advocates for little cost as the APSW program dollars are already allocated through MCSS.

"This makes good fiscal sense and ensures a conflict-free support and continuity to those people who are developmentally handicapped."

**Mr Malkowski:** I just would like to clarify. The Advocacy Commission and the advocates themselves will be arm's length from the ministry; the Advocacy Commission will not be providing services. So therefore there should not be any conflict of interest. As well, the advocates may be able to support the current work that is going on of advocates already so that they can help achieve the goals the advocates have already established.

Another APSW group or other groups who provide advocacy services have not seen the creation of the Advocacy Commission as duplication of services. So do you agree to those couple of points?

**Mr Corini:** We do not see it as a duplication of services at all. As a matter of fact, the reason that the APSAO has been asking to be transferred either to the Advocacy Commission or to the office of disability issues as a parallel support to the Advocacy Commission is to support. We do not see any conflict in that.

Our concern at the present time, one, is that the commission, as it is set out today, will have great difficulties in covering all the demands that will be placed upon advocates to respond to all the needs for all the people in the province who need advocacy services. The other is that fiscally I think it makes sense to transfer the program that is already operating as an advocacy system in a sense, but with a lot of problems because of the conflict of interest, in support of the Advocacy Act. That is what we are saying. We do not see a conflict between the two, but actually one supporting the other.

**The Chair:** Mr Tennant and Mr Corini, on behalf of the committee I would like to thank you for taking the time out and giving your presentation this afternoon.

PAT CHEFURKA

**The Chair:** I would like to call forward our next presenter, Pat Chefurka. Good afternoon. Could you please identify yourself for the record, and then proceed.

**Ms Chefurka:** Thank you. Yes, I am Pat Chefurka from a farm near London. I have a scientific background, a

lot of political involvement and experience both personally and through friends with dysfunctional persons. Our ad hoc group of a psychiatric nurse, Sonia Lee Jackson; a nurse with a schizophrenic daughter, Charlotte Lefcoe; a lawyer, Andrew Bolter, and myself worked our way through this fascinating and confusing legislation, spurred on by our frustrations and feeling of helplessness vis-à-vis some specific problems with the mentally ill.

Bills 74, 108 and 109 all start with definitions, but there is one definition that is missing: a human is a rule-creating animal.

The purposes as laid out in Bill 74, section 1 are very noble and we appreciate the difficulties in drafting legislation to cover the whole spectrum from physical through chronic to psychotic illness. We also appreciate the need to protect the rights of the voluntary patient who may need supportive assistance for a short time. However, what we find here is a system that is far more complex, bureaucratic and expensive than we feel is necessary, and, for seriously mentally ill people, is distinctly counterproductive.

With regard to the proposed advocacy legislation, we wanted to say, "Scrap it and start again." But perhaps something along the line that was proposed by the Canadian Bar Association that would be reactive rather than proactive might be the way to go. Court applications should be avoided as far as possible in order to permit quick response by families and/or those with power of attorney.

With both the Substitute Decisions Act and the Consent to Treatment Act we feel strongly that mental illness should be dealt with separately from physical and chronic illness. It is imperative to recognize the difference between decisions made by a healthy, functioning brain and those made by a dysfunctional one.

Before we get to specifics, I wanted five minutes to deal with a picayune point that bugs me: the flagrant misuse of commas in the legislation. In almost every subsection that has an (a), (b) and (c) that continues the sentence, there is a superfluous comma.

In the Advocacy Act, Bill 74, subsection 7(1) states that, "The commission shall, (a) promote respect for vulnerable persons and for their rights, freedoms, autonomy and dignity." Two of the things that we thought were very important that were missing there were the health and safety of the vulnerable persons.

These bills continually emphasize rights and freedoms, but as Fuller Torrey writes in the Wall Street Journal, "The freedom to be insane is an illusory freedom, a cruel hoax perpetrated on those who cannot think clearly by those who will not think clearly."

The current legislation and the proposed legislation require that no care be provided unless the person actively seeks treatment or is clearly dangerous—physically dangerous, that is. Harassment does not count. Since people with schizophrenia and other serious mental illness typically refuse treatment, it prevents families from doing anything. For those families, nothing is the hardest thing to do.

This freedom also impinges on the freedom of others. There is a big guy named Gerry in his 40s who has decided that the hall in front of my friend's office is a good

place to call home. He uses the stairwell as a urinal, and he craps whenever and wherever. She calls the police. They remove him, but they cannot commit him to hospital. He has not hurt himself or anyone else. So a few hours later he is back. Do we not have a principle in this country that says, "Your freedom ends where my nose begins"? Does society have to yield selflessly to the sometimes selfish desires of the mentally ill person?

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Another fallout is that an estimated 30% to 40% of homeless people are such because they are seriously mentally ill. Many of them have disability pensions, so they can afford an apartment, but they have problems functioning well enough to get one. They often lose their money and are frequently victimized by others—for example, getting \$3 in change from a \$20 bill when they bought a \$2 item. Sometimes landlords are loath to rent to them because of maintenance problems. Some who do have an apartment often will not go back to it because they associate it with the voices they hear that they want to avoid. My friend's daughter, Martha, pulled ceiling tiles down to get at those voices, and the only food in her apartment one day when I was there was a bag of onions. The fact that she cannot care for herself does not permit her being committed to treatment.

Our aim should be to get such people off the streets and into treatment. The proposed legislation mitigates against this because (a) it is so difficult to get these people to a doctor or a mental health facility voluntarily, and (b) on those occasions when you do, the advocate comes along and tells them it is their right to refuse treatment, period, game over, back to the street or to devastated families.

General comments about the Advocacy Act:

1. It is hugely expensive: the commission, the advisory committee, their staffs, offices, services, the army of advocates and their offices and services. Our estimate is that 50 to 100 advocates might be required for the city of London, which at \$30,000 a year might mean \$2 million to \$4 million. This is guesstimating, I admit. For a population at any particular time of 6,000 people in facilities in London, I do not imagine you could figure on an advocate being responsible for more than 100 people at one time; so you are talking 60 people, according to that arithmetic, acting as advocates. I do not know if the government or any of the civil servants have figured a cost factor, but we figured that populationwise London represents a thirtieth of the provincial population, and then you are talking \$100 million or so. We say, would there not be a greater bang for those bucks if they were spent on treatment programs and care givers? Many could then return and become contributing members of society.

2. It is hugely cumbersome. Who is going to write—or read—all the reports required, the requests for consent, get the warrants from the justice of the peace, do the record searches, scrutinize all the advocates, hire all the lawyers and organize court time, judges and staffs? Will everyone in the province have to arrange a power of attorney for themselves? One of my lawyer friends says, only partly in jest, that every new act guarantees each lawyer in the province another \$100,000. Dr Brian Hoffman of Mount Sinai

Hospital says that if you want to certify and declare someone incompetent, by the sixth week you have filled out 45 legal forms. This of course is under the current legislation. Will it be different under the proposed legislation?

3. It is difficult to require sufficiently high standards of training and integrity for advocates, most particularly for those who are volunteers. How would confidentiality be policed? After all, even the professionals screw up.

4. Clause 7(1)(b) provides that the Advocacy Commission act as a lobby group, a function we question as being appropriate for a publicly funded body.

5. Sections 16 to 23 on rights of entry give advocates more power in this area than the police have. We wonder if that is appropriate, particularly if there is a large volunteer sector.

On the Substitute Decisions Act, an interesting observation off the top is that there are twice as many sections dealing with property as dealing with the person. What does this tell us about our society?

What we have here are examples of what we felt were inconsistencies and confusion in the proposed legislation, and I have a number of examples here.

In the first example, subsection 7(1) says a continuing power of attorney gives authority that may be exercised during the grantor's incapacity to manage property, but section 15 says that if the grantor ends up in a psychiatric facility—in other words, he is incapable of managing property—the power of attorney is out and the public guardian and trustee is in. Then you go to subsection 17(1), which says the person with the continuing power of attorney may apply to the provincial guardian and trustee to become the guardian of property, and then subsection 17(9) says the guardian has to manage the property in accordance with a management plan. A management plan? Who makes it, who monitors it, who reads the reports, who acts on it? Why not avoid the whole schmeer by leaving the original power of attorney intact and with some authority?

By now you will realize that we are coming up with a lot of questions. I hope you are all paying close attention. I will expect you to turn in your answers at the end of the period.

**Mr J. Wilson:** Just the government members.

**Ms Chefurka:** Example 2: Subsection 9(3) deals with a case of continuing power of attorney which comes into effect when the grantor becomes incapable of managing property. If it does not also specify a method for determining the grantor's incapacity—and how many would?—then it only comes into effect when there is a certificate of incapacity. Subsection 16(1) says an assessor may perform an assessment. Subsection 16(2) says the assessment shall not be performed unless the assessor tells the person of his right to refuse to be assessed. What schizophrenic in his right mind would permit himself to be assessed?

Example 3: Suppose the hurdles in example 2 are overcome and a certificate of his incapacity is issued. Along comes, "promptly," an advocate who tells the person he has the right to refuse the statutory guardianship. Now what?

Example 4: Subsection 20(2) says statutory guardianship is terminated by notice to the guardian that the patient has been discharged—now, discharged does not necessarily mean cured—or simply by notice given by the person—again it does not indicate whether he is cured or not—to the guardian. All an advocate needs to hear is that the person wishes to terminate the guardianship.

On to part II: Part II seems to lack an appreciation for current and future advances in the field of mental dysfunction. Developments in microsurgery and laser surgery need to be accommodated. Prohibiting research might mean never finding the route back from incapable to capable.

Some more examples, number 5: I do not get all this business about validation. Subsection 47(9) says that a power of attorney for the person is not effective until validated. Subsection 49(1) says the attorney may apply to the PGT to validate the power of attorney for the person. But in Bill 109, sections 13 and 16 say the power of attorney instructions are valid even if the power of attorney has not been validated, and clause 49(4)(c) in Bill 108 says the advocate tells the person that he has the right to oppose the validation.

Example 6: Subsection 55(1) in Bill 108 says, "An order appointing a guardian of the person shall include a finding that the person is incapable," but how is this to be obtained if the person refuses to be assessed, which is allowed in the act?

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Example 7: Subsection 63(3) requires that the person having full guardianship "make decisions on the person's behalf that are likely to promote the person's wellbeing." However, if getting the person into a psychiatric facility would be best and the person objects, then section 56 says that he cannot be put in. What on earth are we going to do with our friend Gerry?

Remember all the questions about the management plan? They all apply equally to the guardianship plan. It strikes us that Bill 108 has a high potential for using up a lot of court time to little purpose. Are the courts the best forum for making these determinations?

On the consent to treatment bill, example 8: Under section 10, when a doctor finds a person incapable, she must tell the person—in writing, yet—he is entitled to meet with an advocate and to apply to the Consent and Capacity Review Board. Under section 10(2) the advocate comes and tells him the same thing, and under subsection 10(5) the advocate helps him get a lawyer. Meanwhile, the doctor cannot do anything until the board makes a decision, and if it is appealed, the appeal is dealt with. Even if the decision is not appealed, the time for an appeal must elapse. What delay does this represent before treatment can begin and where would the mentally ill person be all this time?

Schizophrenics are particularly likely to take up an advocate's suggestion that they can apply to the review board, and the board has the capacity to overrule a health practitioner's finding of incapacity. Not only does this result have dubious validity, but in my friend's experience with her daughter Martha it took a three-hour hearing attended by her psychiatrist, two lawyers, a board member, a

mother, a brother and two witnesses she called to speak on her behalf. No wonder psychiatrists are prone to discharge patients rather than go through this process.

The possibility exists that if a person in the early stages of schizophrenia were taken to a hospital and no advocate intervened, then he might be more likely to accept treatment. In any case, we do not want to see the advocacy and review process undermine or sabotage the treatment team for the seriously mentally ill. We also do not want patients and health professionals in an adversarial position.

If dollars can be saved on the advocacy and substitute decision systems, would it not be wonderful to have more support for families, more people like social workers who could make follow-up visits to discharged patients to make sure they were all right, staying on their treatment program and not on the street?

When you review the legislation, please also remember the rights, needs and safety of family care givers as well as of vulnerable people. Something less expensive, less bureaucratic and more functional for the mentally ill is what we hope to see.

I have included a few specific points in an addendum that I do not think I have time to get into here, but presumably somebody will look at them in conjunction with legislative review.

**The Chair:** Thank you very much. I am sure they will all be looked at by each of the members. Questions and comments?

**Mr Poirier:** Between the theoretical and the practical, you who work in the practical obviously found a lot of places where you have a lot more questions than you have answers, and I cannot blame you. I just hope that Gerry does not end up getting elected to the Legislative Assembly or we are in deep trouble.

I want to thank you for bringing this forward. I just hope that legislative counsel and the government will take that into account and put themselves in the shoes of practitioners and people who have to deal with it in the everyday life of this. How does the intent translate, and try not to mess up the valuable time you have and the resources you have to put to serve and help and all the good faith you have to help the people who are your clients? I thank you for bringing it forward. I can only say we have heard these arguments many times before and I am sure it is not the last time we are going to hear this. Thank goodness you took the time to come forward to bring this, and we can only say to them, "Deal with this."

**Mr J. Wilson:** I do not have any particular questions either, except to say that a number of the examples you brought forward are issues we have brought forward and other witnesses have brought forward also.

**Ms Chefurka:** I am not surprised that you have heard some of these same things before. My only hope is that if you hear them often enough, changes will get made to accommodate these kinds of problems.

**Mr J. Wilson:** It is certainly needed around here. Repetition is needed to make changes. I can attest to that, having been in on the health professions legislation. The more the merrier. Your good humour in bringing this for-

ward, whether it was intentional or not, is appreciated on a Friday afternoon. I am almost tempted—

**Ms Chefurka:** I am surprised to see anybody here.

**Mr J. Wilson:** We are too.

**Mr Poirier:** What perception do you have of us?

**Ms Chefurka:** TGIF extends through the society.

**Mr J. Wilson:** That is right. It could take a while. I am almost tempted to ask the parliamentary assistants to respond to your examples, but that may take a while and I will let them off the hook. It is within our authority to ask for a response to all your questions from legislative counsel or somebody, but I will not. Needless to say, I hope the government will take the time in its five minutes to respond anyway to a couple of the examples that are particularly horrendous.

**The Chair:** Obviously we have struck a chord here. Each of the PAs wants to make a comment or ask a question.

**Mr Wessinger:** I would like to get your perspective on the record here with respect to this whole question of treating the mentally ill, because I think that is really the area you have raised. It seems to me we have two values that are very important with respect to this question of how we treat those who are perceived to be mentally ill.

First of all, would you recognize the aspect that is very important, that we protect individual rights and freedoms in our society? Would you agree with that?

**Ms Chefurka:** Yes.

**Mr Wessinger:** Also, I think it is fair to say that we have as a principle that if people are ill, we should try to get them better. I think that is a principle too and I think you would agree that legislation should try to balance those two views.

**Ms Chefurka:** Yes, distinctly. What I am worried about—

**Mr Wessinger:** Would you also agree that in the question of weighting those values, individual freedoms and rights have to take precedence over treatment if there is a question of doubt?

**Ms Chefurka:** What bothers me is that there has been a switch from the right to treatment to the right to refuse treatment even if that decision to refuse treatment is made by the same brain that needs treating. To me it is complex. My lawyer, Andrew Bolter, could not be here today. I wish he were, because he is able to cope with questions like that a little better than I can.

I know it is difficult and confusing. I am putting out my druthers. I want something that permits mentally ill people to get treatment.

**Mr Wessinger:** I understand your perspective in wanting to have mentally ill people to get protection, but let me say we have also heard from members of the Ontario Psychiatric Survivors' Alliance, where people have been misdiagnosed with respect to the question of schizophrenia, particularly women who have been sexually abused. I have encountered that much in my law practice as well.

The other things is that there is a great failure rate with respect to the whole area of psychiatry, and I think that is

fair to say. With all that aspect, it is very important that we have protections with respect to individuals' rights because of people who have been abused and have been victims of the system.

**Ms Chefurka:** Yes. There is no doubt that in the past people have had dreadful experiences through the system. The sympathies are all there. My hope is that we can improve our treatments and treatment systems. I also hope that we get more supportive systems for help for people in the community who have gone through a program and are back into the community, follow-up services, services for families. For example, the families, as a rule—not always, but as a rule—are the people the most interested in the mentally ill person. Yet they are also victimized by these same mentally ill people. Again, you have to balance some rights here.

**Mr Wessinger:** If I just might follow that up, you would agree that competency is the issue, right?

**Ms Chefurka:** Yes.

**Mr Wessinger:** It is really a question of whether a person is competent. If you determine they are competent, they should be able to make their own decision.

**Ms Chefurka:** Yes.

**Mr Wessinger:** And if they are incompetent, somebody else—

**Ms Chefurka:** But then who is making the decision? Is it a group that does not have the appropriate professional background or is it a court?

**Mr Wessinger:** Do you have more confidence in psychiatrists to make that decision or do you have more confidence in an independent body? That is a question—

**Ms Chefurka:** I would not touch that one with a 10-foot pole.

1520

**Mr Wessinger:** I think the perspective of this legislation is that we have an independent—

**Ms Chefurka:** It very much depends on what people are involved in doing the assessing and decision-making.

**Mr Wessinger:** What I would suggest in this legislation, where you have a situation where an individual does not have capacity and it is determined he or she does not have capacity, is that it improves the situation with respect to treatment of that individual.

Unfortunately you were not here the other day. There was a great deal of discussion with respect to the Substitute Decisions Act. In effect that act creates the possibility of a guardian being appointed to determine the treatment for a particular individual. Like your Gerry situation, a guardian could be appointed under the new legislation, there could be difficulty and he or she could prescribe a treatment process. I would suggest to you that if the person is found to be incompetent, the legislation allows somebody to be admitted to hospital by the substitute decision-maker.

**Ms Chefurka:** We would like to see alternative systems to what exist right now in any case that make it easier and less legislatively complicated to get people like Gerry in

for treatment and get him back to being a contributing member of society.

**Mr Winninger:** Mr Wessinger certainly stole a bit of my thunder, so I will not have as much to say as I originally intended to.

You raise a number of legitimate points and some of them can be answered now. Obviously, due to the constraint of time, some might have to be answered at a later time. You raise one point, with regard to example 6 on page 7: How can you obtain an assessment if the person refuses to be assessed? I would just direct you to read section 76 at some point.

**Ms Chefurka:** I already did. But again, it requires the legal route to get through section 76 to get the person to hospital. What I was hoping you bright people would come up with was a way to get people in for treatment quickly and with justice, fairness and dignity and all the rest of it but without having to use the time delay and the complications of going the legalistic route.

**Mr Winninger:** Since you were not here over the last couple of days, you might at some point want to review Hansard with regard to some of the enhanced powers the substitute decision-maker will have that he or she would not have enjoyed under current legislation, as Mr Wessinger said, to have a patient admitted to a psychiatric facility on a deemed-to-be-voluntary basis, but also to consent to that person's treatment.

By making this vehicle of substitute decision-making guardianship available, we actually provide a tool for the families of schizophrenics to deal with this revolving-door situation, where once they get the patient in and the patient is given medication and starts to improve, he or she checks out and stops taking medication. With a continuing guardianship order, you obviate that possibility until the guardianship might be formally terminated, so there are some tools that would give solace to the families of people you have described.

**Mr Malkowski:** A person with schizophrenia and the family of course are both impacted. It is a tough situation. I think that is a given.

Psychiatric survivors and schizophrenics have come to me and talked about their experience. A lot of people have been falsely diagnosed as schizophrenic. They can receive treatment that is not helping for many years and in fact makes them worse.

Some of these people were victims of sexual abuse. Some of them had some other damages done through child abuse and neglect and those kinds of things, and the professionals then labelled them schizophrenic and they were forced into treatment against their wishes. Not all schizophrenics are labelled like that, although there are some, according to some survivors of some of these psychiatric institutions we have heard from.

I wonder how you account, then, for their support? What about those people who have been falsely labelled schizophrenic and who are in an institution? How would you then support them and get to those people? Aside from true schizophrenics, how would you deal with something like that?

**Ms Chefurka:** Legislatively?

**Mr Malkowski:** Yes.

**Ms Chefurka:** That is where I get into—

**Mr Malkowski:** Specifically, in terms of legislation like Bill 74, that legislation we feel will help people who have been wrongly labelled and are in institutions now.

**Ms Chefurka:** The presentation I was here for was the Canadian Bar Association's one. I thought at the time that what they were proposing did provide that kind of protection. They were talking about situations that needed some kind of attention and review, and unfortunately I did not get a copy of their presentation, so I cannot tell you specifically what was in it or whether in fact it does answer your question, but at the time I remember thinking, yes, that kind of thing would guard against this sort of complication.

**Mr Malkowski:** So it would be fair to say you would agree that the Advocacy Act may assist those people who have been wrongly diagnosed and then are forced into treatment? Would you feel this would help that group in society?

**Ms Chefurka:** Yes. You see, I did not go into all those areas where I agree that the system would be helpful. What I am aiming at is getting the change I feel could be improved, but yes, there are lots of cases and uses for advocates. Just getting a system of advocates that is not too complicated and bureaucratic is the aim I am after.

**Ms Carter:** I think you put one side of the debate we are having very well, and I wish you had been here to hear some of the other side, because it is very moving and very cogent.

I think we should emphasize that the purpose of Bill 74, the Advocacy Act, is to tip the balance, if you like, in favour of the individual, the person concerned, in this case the vulnerable person, the person who may or may not be mentally ill, and to make sure that his or her interests are protected.

I think maybe the most powerful way I can put this is to say, if somebody in your family said you were incompetent and tried to have you committed, for whatever reason—maybe because you were a nuisance or to get control of your estate or whatever—would you not want there to be very strong checks and balances in place to make sure that process was not too easy for them?

We can look at this either way around, and I think one point here is that there is a very big difference between looking objectively at psychiatric treatment, what happens to patients in mental hospitals and so on, and the subjective view of that. I have not undergone that, so I cannot give you the subjective view, but the people who have undergone it give a very consistent view and it sounds very different from that of the person on the outside saying that it is to their benefit to go in there and be treated.

You were talking about things maybe being better in the future than they have been in the past, but it does not sound from what we have heard as though those abuses have been, so far, overcome. We still have medicines that work in making a person more tractable, if you like, but which subjectively are very unpleasant, which have long-

term side effects which are very distressing to the person and so on. So there really are two sides to this.

On a more specific point, you said that the rights of entry under the act are more powerful than those the police have. I think the point there is that the objective is very different. The police, if they go into a home, for whatever reason, can do very drastic things when they get there, like taking somebody's child away or arresting somebody or whatever, whereas the purpose of entry of an advocate is only to be able to communicate with some vulnerable person who is on those premises, that is all, and to find out, hopefully, what their wishes may be and to communicate those wishes. If that person does not want them there, he can ask them to leave and that is the end of it.

Also, when you talked about a vast number of advocates being needed, say, in London only, I believe the total suggested number, other than those who might come under independent voluntary organizations, is only 150 for the whole province. So there is not this army that is about to overrun the province and deplete the provincial treasury.

1530

**Mr Winninger:** But 100 of them would be in London, according to you. How many would be in London—60?

**Ms Chefurka:** There would be 60 for London. It just seemed to us that in terms of the numbers in the province, if that was the total number for the whole province, they would be overworked like crazy. How could they be available for 24 hours a day and this kind of thing if there were only that small number in the whole province? I do not know. I have nothing firm to base that on. Maybe some experience will be needed over time to find out what is an adequate number. Looking at it from our lay point of view, I could see a huge number being required to fulfil all the functions as laid out in Bill 74.

**Ms Carter:** Which is, in a way, to say they are badly needed?

**Ms Chefurka:** No, it is a way to say that maybe the legislation is more complicated than it needs to be. I know the support is still there for people who still need it, particularly the speech-handicapped ones and so on. Sure, they need to be treated properly; they do not need to be treated as if they are mentally underdeveloped just because they have a speech difficulty. Sure, advocates and interpreters and all this kind of thing are going to be needed. But I am hoping that you and the staff will come up with something that is less complicated, less expensive and more effective for the seriously mentally ill.

**The Chair:** Ms Chefurka, on behalf of the committee I would like to thank you for taking time out this afternoon and giving us your presentation.

**Mr J. Wilson:** While we are changing presenters I have a question for the parliamentary assistant. Given your remarks just now and Mrs Carter's, you said that psychiatric services in this province have been a failure. Mrs Carter made it clear that the intent of this bill is to tilt the balance in favour of the vulnerable. I would like to know on what basis the Ministry of Health or the government says that psychiatric services in this province have been a failure. We are going on the premise, I think, that—and I am waiting to

be proved wrong—the stories we read about in the paper are the norm.

I happen to know a number of people who have had psychiatric services, who are very well-functioning people in this society today, who in their youth or something may have required services and indeed shock treatments. There are a number of success stories. I want to know what studies are around—I would be happy to read them myself—as to what extent the system is failing. That would give me an indication of what the need for this legislation is, rather than taking psychiatric survivors' testimonies as being the norm, because I know it not to be in my own personal experience. It seems to be the basis on which this legislation is premised.

**Mr Wessinger:** I think that is a good request. Certainly from anecdotal evidence—we do not have the statistics—you are quite right. It would be very useful information to have to know to what extent the psychiatric services have proved to have a beneficial effect and those that have been unsuccessful. The success rate would be very interesting to look at and I would certainly ask the Ministry of Health to provide that to the committee. I would like to have that information myself, quite frankly. I think it would be very useful to have.

MELANE HOTZ

**The Chair:** I will call forward the next presenter, Melane Hotz. Good afternoon. Could you please identify yourself for the record and then proceed?

**Mrs Hotz:** My name is Melane Hotz. I live in Ottawa. I was the public guardian for Alberta for the last half-a-dozen years or so. I found this process very interesting to watch from there and to return to take it up right here. I am trying not to say, at any moment, "This is how we did it," because it is different everywhere you go. Alberta is, as people are saying, "breaking new ground," and I hope that helps the construction industry so you will have money to pay for this piece of legislation.

**Mr J. Wilson:** You will never get a development permit.

**Mrs Hotz:** Right on.

I have given you a summary of my key recommendations for those who have heard these in many forms over many weeks. I really admire the effort and energy you are putting into it. I got a red carnation for coming here today, but I do not know what you have got for all these weeks of work.

In the main body of the report which you have, I am attempting to comment on the three acts that I have had time to study quite carefully. I am not going to talk section by section by section, although naturally that is a temptation. I would like to just address with you some of the things you may expect to happen, and perhaps we should run a lottery on the outcomes and make some more money that way.

You have been studying this for a long time and it is very impressive. But however long you study something as complex as this, it is not going to come right the first time, and you have to go forward with something. The only question is: To go forward with the least risky bits? I

am suggesting that some of the things in this legislation are going to take away people's rights prematurely, other things are going to cost a great deal of money in relation to the benefits that they may provide, and that the key role, the formalization of advocacy, when put in place together with the other two bills, may cause you a lot of problems, because as yet it is new territory, it is undefined and perhaps there needs to be some staging.

So here we go. Let's look at advocacy first. It is the thing I know least about, so I will talk about it first.

It should, at its best, reduce the number of guardianships and I would applaud that. As a former guardian, I think guardianship is what everybody should try to avoid as long as is safely possible. In my experience, it is an invasion of people's rights and it reduces adults to the status of children, and once you get under it, you cannot get out.

Advocates therefore have a role, if properly played, to ensure that you do not have to have a guardian unless it is really necessary to act as intervenors and to act as watchdogs on what happens in the community.

The courts are important. There were some comments earlier—and I am really pleased I was here for the previous presentation—most of which I heartily endorse. So that gives me double time. The courts are really important.

Physicians have a special relationship with their patients, and their assessment of their patients is properly in the area of consent to treatment, to care by them. To expect functional assessments that attempt to address every part of somebody's life is, I think, too much. They were not trained for it and they have not got time for it.

So my first recommendation is, get your advocacy legislation going first and deal particularly, please, with the issue of non-instructed advocacy. There is a term that was bandied about a few years ago, perhaps in the 1960s: "prisoners of benevolence." Do not make people who are mentally incapable "prisoners of benevolence," because advocates, by their very title, are supposed to do only the best things for people. This can be pretty intrusive, and I think they could be charter issues around an advocate's involvement in non-instructed advocacy.

I also believe from what I see in Ottawa, where I work now with Citizens Advocacy, Community Resources for Disabled Persons and the Council on Aging, that it is very different dealing with people who can participate in what is going on to some extent than with people who are mentally incapable. How you do that is different, and you should know, before you say you are going to do it, how you are going to do it and what the implications are. I am concerned that the commission will be left to deal with this and develop those policies on implementation at the same time as the two other acts that deal with mentally incapable people are in place. Here we go on Valentine's Day.

1540

The second recommendation I have is—again, this was fortunately raised before, so I will just echo it—make sure the commission has some representation of people who are not able to instruct. Otherwise the membership may be persons who are strong advocates for disabled groups who are able to participate, and the others will be shuffled off.

The role of advocates is a very heavy one. I would not like to carry a message to somebody who was apparently incompetent that, "The doctor said you really don't know what's going on so so-and-so is going to decide for you, or you can go to a tribunal if you like." I would not really like to be the one to go and tell an older person that there is a suggestion that he or she should have a guardian to make decisions for him or her. This is going to be very difficult.

On the other hand, the legislation seems to have a catch-all phrase: If a person does not understand, despite the advocate's best efforts, that is all right; they can go away again. Those people are therefore not going to be able to have their own concerns brought forward because it was impossible to communicate with them. Some of the points made by the earlier presenters today raised that very issue: how very difficult it is going to be to carry these difficult messages to people whose ability to comprehend, and the shock of the very situation, is going to run interference.

I do not think you can ask volunteers to do this work. I think it is crass, and it is probably not according to a statute. If two statutes say that advocates have to do certain things, then that becomes a staff role. The comments made earlier that you should separate these functions—I had not thought it through to that extent—but perhaps that is one of the problems: the act is trying to do a great deal for people whose needs are different, and the processes need to diverge as they become more formal and more deliberate.

I am concerned. I am sure the drafters know that commission members and advocates will, by inference in the eyes of the public, become involved in court cases. There are a lot of court cases involved in this stuff. Some of them are ridiculous, but some of them are very well taken. Advocates, who are the people visiting, and commission members, who are empowering advocates, are likely to be dragged in. There seems to be no definition. Is an advocate any person under the act? Will there be pressure on advocates to bring forward cases themselves, or will they be specifically excluded from doing so? I do not notice anything in this. So we now have done with Bill 174—and five minutes.

Consent to treatment: I am getting to the one I know well. Now we are in the middle somewhere.

**Mr Poirier:** Watch out.

**Mrs Hotz:** Watch out? You mean you are going to be after me then?

**Mr Poirier:** No, no. I am quoting—

**Mrs Hotz:** I can never get there; I can keep you here till six o'clock before I get there.

Consent to treatment: I know this area well, because the most things public guardians have to do is consent to treatment. When at the end we get to the statistics of what public guardians do—the exciting numbers—you will find out about that. Right now I am concerned about the determination of capacity to consent.

I am concerned about these advocates getting involved as well as physicians. I think we all know that physicians are busy people. They are paid for certain procedures. The

assessment of capacity, in the way you envisage, is not one of those procedures.

I do not know whether placing advocates out there in the community to carry messages and arrange for reassessments helps either the physician or the advocate or the patient. There was a study in Ottawa where physicians were asked whom they prescribed medication to—without doubt, tranquilizing medication—and the ones they remembered least were the older people, how much they gave. They consistently underrepresented how much they prescribed for older people. There is another study that shows that the older you are the less your doctor will talk to you.

How then, if this is the prevailing climate of relationships between physicians and their aging patients or by inference their less competent younger patients, are you going to really expect to get a high-quality assessment of functional competence done?

On the other hand, is it not the business of the professional regulating authority to teach doctors how to gain informed consent and how to deal with patients who are less than competent and old? Do we need advocates out there to keep them honest or to fill in the gaps?

I am not sure also whether a test prescribed by provincial statute is one that will help them or will be accepted readily as an alternative to their own determination for consent to treatment. I do not know, even following the excellent work done by the Weissstut committee, whether there is such a thing as a generic, acceptable test of competence. You have heard many others who have said the same thing. What are you going to give people to do that is going to make you pretty sure they are doing it right; that when they send out that advocate, that message is an okay message? There will be a lot of ramifications if it is not.

Repeated assessments of capacity: It seemed to me, reading it, that the best things are: "Don't make general decisions about anybody. People change; situations change. Therefore, every time you have to test." Again, I know that is the way it should be done in principle, but I am wondering in practice if you can expect all the health practitioners in Ontario to apply a test every time they have doubt about a particular treatment. We might get too many full guardianships as a result. It will be easier to get the whole thing over with. As was said before—it is a word that can go in Hansard here—"Let's do the whole schmeer."

Administrative procedures: There are lots of them, and who is going to pay the physicians for doing all the stuff? Estimates were done of what advocacy would cost. Has anybody done estimates of what it is going to cost physicians and under what provisions they are going to be reimbursed and by whom?

In Alberta—there, I mentioned the A word—the Alberta Medical Association developed a fee scale: \$75 to \$250 for an assessment. These assessments were done on something called a Form 1 that had about three lines in which to say why, in the physician's opinion, the person needed a guardian or trustee and to sign it off. It took about 15 minutes to complete.

If you knew the patient, \$75 was okay. If you did not know the patient or it was a contest, it could go up to \$250. If you ended up in court arguing about it—I remember one that cost about \$90,000 by the time everybody got in with his assessments of the situation. I am concerned about legal costs because the provision is for a legal aid certificate and otherwise you pay yourself.

There was also a question as to whether Alberta health care covered these third-party examinations. I presume you have worked out already that Ontario health care will cover all these procedures, because there was some concern that it might not.

So I am suggesting you review everybody's role in terms of consent to treatment with a view to simplifying, making sure who is responsible for what, and then, in the best of all worlds, it is going to stop a lot of guardianships, and for that I applaud you.

1550

Let's get on to an issue that was dealt with today. I am sorry Mr Sterling is not here, because of course this is the result of the Nancy B decision. One of the things that happens with mentally incapacitated people is that it is very difficult to let them off this earth. Everybody feels really scared, and I guess the drafters of this legislation felt scared because they did not say anything about withdrawing or withholding of treatment. Withholding of treatment, yes, if you have in your directive that you do not want a ventilator. So they will not give it to you unless modern medical technology is advanced and it might work. But nothing about withdrawing treatment. I have to be careful because I cannot talk about cases, obviously, but the worst time one can have as a guardian is if somebody who is under guardianship has been put on a ventilator over the weekend by a resident in an emergency and then on Monday they start phoning to say, "No reason here. Should pull it off," and there is some young person outside there who wants that intensive care bed.

People have accidents. They fall off motorcycles. People get old and they become useless. The question is, who is going to be making those decisions and how about stopping treatment? All the words that are coming out of Ontario about the cost of health care—this might need to be something you will need to address. There were nursing homes in Alberta that required people being admitted, or those admitting them, to sign what is called a "do not resuscitate" order. "You can't come in here." That is tough enough for families or people to say, "If I have a coronary, don't jump on my chest; don't run me to the hospital in the night." Try that on as a guardian or a power of attorney. Quite a blank cheque to be asked to sign.

I am suggesting that you clarify the issues of consent to withholding of treatment. I notice the public guardian, who is going to be a lot busier than I ever was and with good reason—not that I do not think Mr Paisley does not work hard enough, but the things he is going to be asked to do are very important and they should be added to the jobs. One of them is that he is going to get a notice of incapacity. Every time a physician thinks you have lost it for the last six months and you are not going to get it back, he has to tell the public trustee. Why? Is this a communicable

disease, incapacity? What is he going to do with this information? Is he going to do a proper assessment for guardianship? Is he going to send an advocate in? Is he going to keep your name on a list as somebody who is incapacitated out there, and be ready to be called upon as a substitute consentor? I cannot quite understand why this notice is mandatory, unless it is a way of case finding. If it is, it is a very good way because every time a physician sends in those notices, there is a guardianship order following. What did somebody say about lawyers and \$100,000?

Interjection.

**Mrs Hotz:** Yes, there is part of it in there, right there. I would just like to see you consider why you are going to do that. Legal costs: I do not believe people should have to pay lawyers when somebody else decides they are incompetent and they have to go to court to fight that. Legal aid in Alberta did not cover this sort of action; it was not in their policies. It may be here; I do not know. But even so, it is going to leave out a lot of people who have somewhat more income. They are telling us that older people are getting richer and richer. Is this the way we want them to spend their money, unless their sons are lawyers?

I believe the crown in right of Ontario should cover these costs and that no one should have to pay to defend himself against an assertion of incapacity brought by other people. Responsibility for these costs could deter somebody wanting to contest an assertion. I certainly know, in terms of ordinary guardianship, the public guardian can get a lot of work just because a family does not want to use their money or deplete an estate by paying \$2,000, \$3,000, \$4,000 or \$5,000 for the cost of a hearing. I am recommending that the Attorney General, not the Advocacy Commission, pay for these legal costs, and if not, that you regulate the amounts of them, because they can go right out of sight. Once this thing gets rolling, the procedures get more and more expensive. Alberta went for 10 years without the physicians thinking about how much it costs to do this work, then suddenly the penny dropped.

Sterilization: Let's talk about that one. Mentally handicapped people living in the community get married or they get pregnant. Families who are having younger people of child-bearing age or child-making age, and I guess the child-making age goes on for ever, get really worried about what might happen.

To me, it seems that the right of women who are not mentally incapacitated to decide to use sterilization or to have their tubes tied is one that is not available to women who are mentally incapacitated. Some of them cannot take birth control pills for a range of reasons I will not bore you with. Depo-Provera has been used, and that is an experimental drug. The alternative is abortion. Culturally and religiously and for a whole lot of other reasons, abortion should not be seen as the form of birth control used by mentally incapacitated people. But I do hear that Ontario is looking at this issue of non-therapeutic—I just heard that at lunch, and it looks like this is being attended to in another forum, but it is an issue of discrimination against, as well as protection of, the interests of mentally handicapped women and males as well.

Now we come to the one I know best, and we have just got a mere three minutes. Boil an egg. The public guardian in Alberta fell under the Department of Family and Social Services, and that is why I do not talk like a lawyer. The public trustee worked for the Attorney General, but there was a lot of work in common. Ontario goes much further than this and we all know the good things about enduring powers of attorney, temporary guardianships and all these things that will stop full guardianship.

Let's get back to full guardianship of the person. The problem in Ontario and the one you might have here is that everybody is going to read this act very simplistically and say, "You have to have a legal guardian if you can't make decisions for yourself," and say, "You can't make decisions for a vulnerable person unless you're a legal guardian." That is going to cut out and bring to a halt a lot of very good informal supports that are quite adequate for the conduct of most people's lives. In Alberta many private guardianships were perhaps not necessary. One of the ways people got a guardian of the person was that there was a guardian of property or a trustee being appointed, because often the ability to deal with one's money and the fear that you will give it to the wrong person gets that process going. That is fine except that you do not go back to court twice. What used to happen was that the lawyers and the bench and everybody said: "If you're going for this, go for the other at the same time. Even though they don't need guardianship in all these areas right now, probably sooner or later they will, so you might as well go for the whole"—and I will not use that word again—"you might as well do it all."

Therefore, the aims of the legislation to be non-intrusive can be overtaken by the practical way we all live and organize our affairs. Therefore, in planning, the avoidance of guardianship somehow should be rewarded. Reward the lawyers, reward the doctors, reward the bureaucrats for anything they can do to find other things than guardianship, as long as the person does not come to risk.

I notice there is no requirement for guardians to live in Ontario. You want your guardians of property to live here, but you do not want the guardians of the person to live here now. This is not just going to Florida for two months in the winter; this is for ever. It is really difficult to be a guardian of the person if you do not live in the same province, and they cannot really get after you for not being a good guardian. I think the lawyers in the group will know that that might be a problem.

The other thing is that the public guardian may of course get a lot more work, because if family members who would be guardians are not resident here, that job will devolve on the public guardian. But this is probably an okay situation and the family outside the province could be kept in contact with the situation and still be involved, even though they were not the formal guardian.

1600

I have given you statistics on page 18 that you can read at your leisure, but not surprisingly the public guardians have had mostly mentally disabled adults in institutions to look after and a somewhat smaller number of older people in institutions. Family and private guardians have many

more people living in the community to care about and many more older people.

That brings about another point, which is that time passes. A guardian is not frozen in time. If you pick a power of attorney or a guardian and you are old, chances are they may not be around for much longer. Chances are that the public guardian should watch the demographics of the private guardian population because the traffic is moving in his direction and he never gets old. He is always there.

Burnout is another issue for aging guardians. Being with somebody in the community, and you heard this from the lady sitting here before me, is very tiring. When you are responsible it is even more tiring.

The act provides for custody rights. Younger mentally disabled adults living in the community move around at quite a rate. They do not like where you suggest they should live and they disappear. At 2 o'clock, 3 o'clock or 4 o'clock in the morning the group home calls. The group home will also call the public guardian trustee staff at 2, 3 and 4 o'clock in the morning. This is hard work, and the more community living you have the more interesting and hard it is going to become, so the family guardian really has to be supported. The advocate needs to be encouraged to support family and private guardians rather than take that watchdog role and the finger-shaking too seriously.

Getting to the end, I think you should do some case load forecasts. Six hundred thousand was mentioned. I had 200,000 people under guardianship, but I did not have all the other impellers to guardianship that your legislation may create. You need to know how many people and what is going to be needed for them before you get started off, because this is not something you can put off until next month or next year when you have the funds. These people are out there and the community has expectations. I suggest you move ahead with what you can do in stages and evolve from there.

Public information is really important. I mentioned that before. Legal costs I have mentioned before.

The last thing I want to say is that it is very difficult to reconcile the support of human rights with that of protection. You have tried in this province to put together or cobble together the best of what everybody else has done. Obviously in five years from now you are going to look back and say, "Well, it was a fine effort and look how far we've come." But right now it is a little bit tough. I guess I only hope that in five years you will also be receiving letters from all those other jurisdictions that say, "We'll have what they're having."

**Mr Poirier:** It is most informative to have you here because you have lived in the shoes. You may or may not be ready to apply for Ontario's position to be the next one, right?

It should be most interesting what it would cost and the work load. What do you expect? You have mentioned 600,000. What do you think it could be—a million?

**Mrs Hotz:** It depends on how the legislation is presented to the public. For example, in Alberta, I understand, and it was long before my time because they have had this

legislation for 14 years, every institutional administrator got a letter warning him that at his peril did he treat anybody who was incompetent and did not have a guardian, so there was a lot of action. I think your health consent legislation is saying to physicians, "at your peril." So a lot of the things you put in place are going to determine what comes forward.

The other thing is that nobody should have the impression that to make decisions for somebody who is incompetent is an illegal or a bad act. This is not so. I think your minister, in talking about the Advocacy Commission, emphasized that family and friends and informal support systems are still there. There are very few things that you really need a formal decision-maker for, that you can cry out that your rights are being abrogated. Health care is one of them, and there are ways through your act to get around that. Legal representation is another, and I think there is legal representation already for incompetent people. Decisions as to where you are going to live: If you are already in a nursing home or if you are in a long-term care institution, what decisions are needed to be made that require a court-ordered guardian? So you can keep it down by the other acts you have put in place.

**Mr Poirier:** I see. Thank you very much for coming forward. You have very good insight into what could be seen as the reality of it all.

**Mr J. Wilson:** Thank you, Ms Hotz, for a very informative presentation. It is very good of you to come before the committee, especially with the amount of experience you have. I would agree with most things you have brought to our attention. I would not agree and I do not think you meant that many people get older and become useless. I do not think you meant it in the way it may have come out.

**Mrs Hotz:** I am sorry if it came out that way. Not at all.

**Mr J. Wilson:** It may have offended some.

Just continuing on Mr Poirier's point, though, you mention that if the government were to do this and it were done properly, it may cut down on the number of guardians required. But one of the things I do like about the legislation is in Bill 108—and what Mr Winninger was explaining before and Mr Wessenger—in the case of a schizophrenic, I can see the way the legislation is set up that a number of families will be tempted to, as you say, get whole guardianship as soon as possible, as soon as they can get a court date, because, notwithstanding the Mental Health Act, the provisions in this legislation do appear, anyway, to make it easier to have a schizophrenic undergo treatment. So I am a little confused. Are we going to have more guardianships or fewer guardianships?

**Mrs Hotz:** We had very few people under guardianship who were just mentally ill because it was necessary that you could not make decisions on a continuing basis, and mental illness is something cyclical. Also, people who were that ill that they were incompetent were usually under certificates in psychiatric hospitals. The people who were under guardianship who were mentally ill were usu-

ally also mentally incapacitated, that so-called dual diagnosis group, and it was that that drove the guardianship.

**Mr J. Wilson:** You mentioned also that one of the dangers of guardianship is that once you are under it, it is pretty hard to get out of it.

**Mrs Hotz:** Yes, and under this act, very much so.

**Mr J. Wilson:** Have you a practical experience on that?

**Mrs Hotz:** Yes. Again, the matters of expediency—and I noticed the assessments for regular guardianship are not as rigid or rigorous as those for durable powers of attorney, and I wondered about that because it just appears to need somebody to say, "I've known this person in the last 12 months and I really think he needs a guardian and here I am." The court can then make a decision as to for how long a person needs to have a guardian.

I do not know whether the charter would require some regular review, but your review is left to when any person brings something to the court, and that seems to be more attached to changing guardians who get tired or whatever or leave than the need of the person for a continuing guardian or the actions of a guardian.

I am really pleased to see that the public guardian trustee has a role to oversee these guardianships. That is just excellent, but it is not a defined role. It is something that he can choose to exercise or not. He may or may not need to ask for the guardianship report to see what a guardian has been doing. But there is nothing in there about the need for guardianship or to assess whether somebody still needs a guardian. We all know that for the people who have guardians probably it is a long-term situation, but if you really want to follow the letter of your intent about human dignity, somebody should be also checking on the need for guardians as much as what the guardian has been doing with the person under guardian at intervals.

**Mr J. Wilson:** Thank you very much.

**Mr Wessenger:** Thank you very much for your presentation, because you have had real experience in dealing with these questions.

I would just like to make sure I am clear on your presentation. As I understand it, what you are saying is that there is a danger in this legislation of having too much guardianship because of the cost both to the private and to the public about having a large number of guardianships. Is that correct?

**Mrs Hotz:** The danger is—

**Mr Wessenger:** —is of the cost of having too many guardianships. Is that your concern?

**Mrs Hotz:** No, I am concerned that getting guardianships is expensive for people.

**Mr Wessenger:** Yes.

**Mrs Hotz:** But doing some of the other less formal processes and going back and forth on health consent is also expensive, so people may go for guardianship once and for all to tidy up the situation.

**Mr Wessenger:** I understand that you would prefer to see more of the situations dealt with under the Consent to Treatment Act and the Advocacy Act.

**Mrs Hotz:** Exactly.

**Mr Wessenger:** Yes. So that those are very important features of the whole package, then, the Advocacy Act and the Consent to Treatment Act.

**Mrs Hotz:** A temporary guardianship is a very good feature in emergency situations. We have all dealt with those. That baby should not go out with the bathwater.

**Mr Wessenger:** The other thing is, am I correct that you question the need for this notice of incapacity as part of the legislation, other than a case study? You mentioned that you felt that sending a notice of incapacity to the public guardian was somewhat unnecessary.

**Mrs Hotz:** No, I am just wondering what it is supposed to achieve. What is the public guardian trustee to do with this information? It almost implies that if he does nothing and something goes wrong, there can be an issue of statutory neglect. So therefore he would be impelled to do something, and because we live in a bureaucracy, guardianship, nice and tidy, might be what results.

**Mr Wessenger:** The other thing I would like just to confirm is, you have indicated that in Alberta the use of

guardianship for schizophrenic patients has not been utilized to any high degree.

**Mrs Hotz:** Not unless there was mental incapacity as well, and I think the previous mental health legislation in Alberta kept guardians out. Once you entered those hospitals as an involuntary patient, all the decisions were made for you in those hospitals.

There have been revisions of mental health legislation all over, and now consent by guardians is more of a viable option, plus people are changing their status from formal to informal very frequently, which they did not do before. So that world may be changing.

**Mr Wessenger:** So it is an advantage to have the voluntary consent through a substitute decision-maker with respect to admission for treatment of a patient.

**Mrs Hotz:** Yes, if somebody is prepared to go.

**The Chair:** Thank you, Mr Wessenger. Ms Hotz, on behalf of the committee, I would like to thank you for taking the time out of your busy schedule to come and give us this presentation today.

**Mrs Hotz:** Thank you.

**The Chair:** Having no more presenters before the committee today, we will adjourn until 9:30 on Monday the 17th of February.

The committee adjourned at 1613.

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## Legislative Assembly of Ontario

First Intercession, 35th Parliament

## Official Report of Debates (Hansard)

Monday 17 February 1992

### Standing committee on administration of justice

Advocacy Act, 1991,  
and companion legislation

## Assemblée législative de l'Ontario

Première intersession, 35<sup>e</sup> législature

## Journal des débats (Hansard)

Le lundi 17 février 1992

### Comité permanent de l'administration de la justice

Loi de 1991 sur l'intervention  
et les projets de loi  
qui l'accompagnent



Chair: Mike Cooper  
Clerk: Lisa Freedman

Président : Mike Cooper  
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# LEGISLATIVE ASSEMBLY OF ONTARIO

## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

Monday 17 February 1992

The committee met at 0941 in committee room 1.

### ADVOCACY ACT, 1991, AND COMPANION LEGISLATION LOI DE 1991 SUR L'INTERVENTION ET LES PROJETS DE LOI QUI L'ACCOMPAGNENT

Resuming consideration of Bill 7, An Act to amend the Powers of Attorney Act; Bill 8, An Act respecting Natural Death; Bill 74, An Act respecting the Provision of Advocacy Services to Vulnerable Persons / Projet de loi 74, Loi concernant la prestation de services d'intervenants en faveur des personnes vulnérables; Bill 108, An Act to provide for the making of Decisions on behalf of Adults concerning the Management of their Property and concerning their Personal Care / Projet de loi 108, Loi prévoyant la prise de décisions au nom d'adultes en ce qui concerne la gestion de leurs biens et le soin de leur personne; Bill 109, An Act respecting Consent to Treatment / Projet de loi 109, Loi concernant le consentement au traitement; and Bill 110, An Act to amend certain Statutes of Ontario consequent upon the enactment of the Consent to Treatment Act, 1991 and the Substitute Decisions Act, 1991 / Projet de loi 110, Loi modifiant certaines lois de l'Ontario par suite de l'adoption de la Loi de 1991 sur le consentement au traitement et de la Loi de 1991 sur la prise de décisions au nom d'autrui.

PETER THOMAS PETER

**The Chair:** I call this meeting of the standing committee on administration of justice to order. I would like to call forward our first presenter, Tom Peter. Good morning. Please have a seat. Would you please identify yourself for the record and then proceed.

**Mr Peter:** My name is Peter Thomas Peter and I am a psychiatric survivor. I would like to make a presentation to the standing committee on administration of justice. I am making a personal submission regarding the proposed Bills 108, 109 and 110.

In approximately April 1985, I was suffering with a number of problems in life and as a result of a decision I made I have for the past six years been unable to function in my normal capacity as husband, father, provider and human being. The decision I made was to attend the Clarke Institute of Psychiatry for some guidance and assistance. I was experiencing problems with my living accommodation and additional problems in my personal life. I was very tired and frustrated and was voluntarily admitted with the purpose of addressing these normal life problems. I spent approximately three weeks on the ward and then left. It was very crowded and none of my problems had been counselled.

Grasping for any extended hand of help, I approached a psychiatrist of the Clarke Institute at the drop-in centre

within that facility. Upon seeing my distress with what was happening in my life, he suggested I be admitted to a regular ward of the Clarke. He told me to be able to remain on the ward I would have to submit to medication as prescribed by him.

I had previously been admitted to the Clarke in 1969 and I was curious and also concerned about health risks with medications and shock treatment and the lack of help addressing the problems I was facing. For fear of ending up without a roof over my head, I felt coerced into submitting to the treatment.

My average dosage of medications left me completely unable to think freely or to consider my problems rationally. The adverse reactions to this include insatiable thirst, dry mouth, falling in and out of consciousness, no equilibrium, dizziness, constipation and thorough confusion. All this occurred without any explanation of the reactions that I may experience. At times I refused the medication and was told that if I did not take it I would have to leave.

After approximately seven days of unpredictable torment and disappointment I was approached by two psychiatrists and told that to speed up my recovery they wanted to give me shock treatment. The treatments would involve a series of 15 shock treatments. After I refused, they certified me involuntarily. My medication was obviously greatly increased then. I assume they considered me incompetent to consent.

To implement their plan to administer shock treatment to me, they contacted my mother and told her they needed her consent for electroconvulsive therapy. They told her it was in my best interests in terms of recovery. I was never certified as incompetent and never gave consent.

I knew the treatment was dangerous and experimental in nature. This was proven to me after, when I experienced both short-term and long-term memory loss. This created a debilitating condition and worsened my original reasons for attending the Clarke Institute. The pain and anxiety this treatment caused could have been implemented more cost-effectively by striking me on the head with a crowbar.

Since psychiatry is not an exact science and I was betrayed by them after placing my initial trust in them, I feel I should be able to gain access to the justice system by filing charges of assault. I have been to see several different justices of the peace, Ontario crown attorneys, the Ontario Human Rights Commission, the College of Physicians and Surgeons of Ontario, the Office of the Ombudsman, the Attorney General and the Ministry of Health.

I was told by a justice of the peace that I deserved what I got and that the Court of Appeal decision meant nothing to him, regarding the recent Court of Appeal ruling that a mentally incompetent, involuntary patient could not be given treatment if he did not want the treatment when he was previously competent.

To my knowledge, no action or investigative work is being done on this matter by all those institutions that could help and have obviously refused to.

I feel the legislation before you must protect the vulnerable from the kinds of totalitarian intimidation I experienced. I would like to see all consent to any questionable psychiatric treatment be voluntary, informed, in writing and verifiable.

I appreciate the opportunity this committee has given to me to speak and present this information to you. I hope the work you do will protect the thousands of other victims who have fallen prey to psychiatric abuse.

**The Chair:** Thank you.

**Mr Poirier:** Thank you for coming forward to present this. Do you have any specific recommendations or observations pertaining to what is proposed? Would you have some comments with specific reference to Bill 74: what you would like, what you would not like? You gave us a general principle of where you stand on this, but do you have anything specific to say?

**Mr Peter:** I think every individual should, no matter what the situation, have the access to choose the line of treatment he or she wishes to receive. I do not agree with the way the statutes of the law have been in place for years and have been ignored for a large part of the industry. I have a great fear or anxiety that this may never be done because they are such very protected and godlike figures in their own minds.

**Mr Poirier:** Do you have a relationship with the Clarke Institute now?

**Mr Peter:** No.

**Mr Poirier:** Have you found an advocate? What is your current situation?

**Mr Peter:** I have tried to lay charges. I have seen everyone of any accountability within the legal and the health fields and I am totally disappointed.

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**Mr Poirier:** You feel like right now nobody is there to help you out, nobody wants to take on your dossier. Is that how you feel?

**Mr Peter:** I feel my basic impact on the justices of the peace—their legal justification is based on the fear or anxiety of even looking at what took place and repercussions and denying me access to the law out of fear, which should not be there and in place.

**Mr Winninger:** I take it you received this electroshock back in 1985?

**Mr Peter:** Yes.

**Mr Winninger:** You were concerned about the side effects, the memory loss?

**Mr Peter:** Yes.

**Mr Winninger:** You indicate on page 3 of your brief that after you refused the electroshock—it appears you refused it—your mother was contacted and she consented.

**Mr Peter:** She consented but—I love my mother dearly, but it was not informed consent, so to speak. She was being very laymanish, not understanding the techniques or

the treatment, but gave it out of their input, "It's in Tom's best interests that he follow this treatment."

**Mr Winninger:** To your knowledge, your mother was never made fully aware of the side-effects at the time?

**Mr Peter:** No, never.

**Mr Winninger:** Have you had any admissions since 1985?

**Mr Peter:** None, thank God.

**Mr Winninger:** But you are still coping with the after-effects?

**Mr Peter:** Trying to cope, yes.

**Mr Winninger:** Are you finding the support you need in the community to do that?

**Mr Peter:** Just like everyone else in this recession, it is dog eat dog out there, and sometimes the social services have a strange attitude.

**Mr Winninger:** Do you think you would benefit from the advocacy that will be offered under our legislation?

**Mr Peter:** I certainly hope so. I took part in the committee meeting down at the Holiday Inn last week, I guess it was, and the design. I sat on the health committee and I thoroughly enjoyed the opportunity of having some input in the social charter for Canada.

**Ms Carter:** I think the intent of the legislation we are putting forward is to empower individuals like you to make sure your wishes are respected. I am just wondering what went wrong in your particular case. Would you say what you needed was help, advice and other support within the community and not psychiatric care?

**Mr Peters:** That is a difficult question. I am involved with the community where I live. I am in a drop-in centre, which is helping me greatly, helping others understand. Although I am not making any money, I am spending my time on different committees, trying to get an impact as an advocate to help and sustain this line of thinking, because there has been a void here for many years.

**Ms Carter:** So we are strengthening the base.

**Mr Peters:** It has not reached my level yet, as I am still in a voluntary situation, but I have applied for jobs at the Ombudsman and in their offer for advocacies within mental hospitals, prisons and everything else, as an investigator. I have been an investigator and have a lot of security experience behind me, plus social experience, people experience with social services. I am trying to get a job, but I guess like everyone else, there are 6,000 people applying for a job.

**Ms Carter:** At the moment you are more a victim of the economic situation than anything else.

**Mr Peter:** Economic, plus there is an overriding cause. I could never do this before. I could never bare myself in public at a job interview or put on my résumé, "Yes, I was in the Clarke Institute of Psychiatry."

**Ms Carter:** When you were in there, was there no advocate who could have helped you in your situation?

**Mr Peter:** At the time, I knew there was supposed to be a patient advocate. I never met anyone. I never met together with the doctors' board. It was never reviewed. I saw the doctor once a week. I was not given any chance to

speaking about the treatment I was receiving and ask them to review it. It was not reviewed. I am not saying I was refused, but I asked about it, so I do not know.

**Ms Carter:** So you are saying if there was an advocate there, you were not consulted.

**Mr Peter:** Who was working, yes, a workable advocate, and if they went by the established law, they would have prevented the treatment I received. That was already in place.

**Ms Carter:** Do you think the present legislation is going to help in that kind of situation?

**Mr Peter:** I certainly hope so, I really do. This is the first time this issue has been seriously discussed. I am really pleased we have an opportunity to bring out things in the open. I am not totally anti-psychiatry but I know there are different ways: there are socioeconomic, there are family problems, there are accommodation—life problems.

**Ms Carter:** So what you are really saying—and I have heard this from other people in your situation—is that we need more alternatives in society.

**Mr Peter:** Sure, exactly.

**Ms Carter:** Other support services within the community rather than having to go into an institution.

**Mr Peter:** Yes, they are very much needed. The community-based district health council is a good project. I do not know whether that is going to continue, but I certainly hope so. I am involved with EMHSA, the Etobicoke Mental Health Services Agency, which has a framework design that I totally agree with. I would love to see this in place. It is going to take time, but it is on the road. This is the thing that will help a lot of people not get down to zero and remain at zero for the rest of their lives. If they want the option to grow and participate, it will be given. I firmly believe that. I think medications and treatments are not the only answer; I think talking, reasoning, enabling people to do things.

**Mr Wessenger:** Thank you for your presentation. It seems to me you were denied some basic rights back in 1985. You had no right to question the finding of incapacity, unfortunately. Is that correct, that you had no rights in 1985?

**Mr Peter:** I did really, because on the medical files I was—

**Mr Wessenger:** No, I do not mean medically you had no basis, I just meant you did not have a legal basis.

**Mr Peter:** I had no access to help, period, other than the concern and love of my mother. Put a mother in that situation and it is hard on everyone.

**Mr Wessenger:** To protect people like yourself, it is very important that you have the right—

**Mr Peter:** It is important that there would be an advocacy program and that the rules are followed.

**Mr Wessenger:** You had no access to advocacy at the Clarke Institute at that time?

**Mr Peter:** None whatsoever.

**Mr Malkowski:** Thank you for your presentation. You were saying you would like to have access. This legislation would respect your right to refuse treatment, because if the

medical profession did not respect that, you would then like to be able to bring legal suit against it, correct?

**Mr Peter:** Correct.

**The Chair:** Mr Peter, on behalf of the committee, I would like to thank you for taking the time this morning to give us your presentation.

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#### WITNESS A

**The Chair:** I would like to call forward our second presenter. I understand you do not wish to have your name used so we will respect those wishes. Please proceed.

**Witness A:** Thank you. My husband and I are parents of an adult son who suffers from bipolar disease, more commonly known as manic depression. The nature of this illness is that it is episodic. Normally he is a perfectly functioning person, able to work. That is why he is not here today. It is controlled by lithium medication which he takes regularly, but we have had several crises in the manic phase. Somehow his state breaks through the lithium and it is during these crises that we need medical help. When he gets into this state he refuses medication. He knows he needs it in his normal state, but because of the mania he gets into a situation where he thinks he does not need it. At this time we have to get him to hospital. He refuses to go to hospital but we have always been able to—not easily—get him there through the help of the police.

I should explain that in the mania he enters a state of psychosis, delusions, paranoia and a state of grandeur. We have no control of him at this time; there is a distancing between us. He has his own agenda that he is following in his delusions and this has at times led to a brush with the law. Luckily it has not been anything too bad, but it usually brings him into the hands of the police, then our effort to get him to hospital.

When we get him to the hospital, the problem is that we arrive at the emergency department and we are confronted with some doctor he has never seen before. We try to explain the situation but we are not listened to. We are just outsiders. What we say has been called hearsay. When we explain his case, this does not seem to be important. What is important is that the doctor there and then makes a decision whether to take him in, whether to give him medication or to detain him, whatever. Of course, a young doctor is going to play pretty safe. He is not going to take him in right away and give him medication. Our situation is different: We are asking for medication at this time.

They cannot detain him. If he is not being violent they can let him go and then once again we have the performance of getting him into hospital. It is not a very easy situation for us. I should say that when he is in this state, with the grandeur and so on, he sounds very plausible. He arrives in front of the doctor—it is very difficult for a doctor. I understand how the doctor, without listening to what has happened previously, on seeing him would think there is nothing wrong with him. This has happened. Two doctors have found nothing wrong and then we have had to go through the whole thing and get him back again later on. They have to decide according to the law; as they say,

the word is "capability" to the treatment. They listen, then they decide if he is capable in the law, which is in Bill 109, subsection 5(5). If they find him capable, they then are able to ask him whether he wants the medication. At this point, he will refuse it. It is only if they find him incapable that, under the Substitute Decisions Act or the power of attorney—and he is willing to make us, or someone, power of attorney or substitute decision-maker when he is in his right mind. He would like to think that when he has made these provisions, they will hold when he is in crisis. But under the law they will not hold, because if the doctor finds him capable, then the substitute decision-maker does not even come into effect, as I read the law as it stands now.

What we are asking here, changing the law, is that he be assured that when he has chosen a substitute decision-maker, has written his wishes and has stated his condition, that at the time of deciding capability this will be taken into consideration. If there is a dispute with the substitute decision-maker then it should be mandatory that the doctor consults with the supervising doctor who is monitoring the whole case, the family physician as it happens with us, so that this sort of mistake—because it could be a very serious mistake. People in mania can be violent to others and to themselves. We have been lucky that it has not been worse than the cases we have had.

Also, time is important too in the progress of the disease. The sooner the treatment, the better. If the treatment is given, it is usually a matter of 48 hours and he is out and he is in control and he is willing to take the medication. He is brought down from the mania and is quickly on his way to recovery again. It is probably a year or two before he has another one of these episodes. But if we do not get it, he could end up just wandering on the street. He usually takes off for the east coast or the west coast and it is very difficult for us then to have any jurisdiction at all.

He is not here today because fortunately he is working. He is a professional and he is in normal employment. But he did write a personal statement which perhaps I could read to you. He says:

"I am fortunate to have my parents as care givers at present and would hope that the law could be amended to help them help me when I am not in control of my thoughts and judgements and able to help myself.

"This illness, diagnosed as manic depression, struck me in my university years and now it is very disconcerting to know that my mind can go so out of control when my body chemistry goes awry. I do, however, know from several past episodes that it can be quickly put into control again with the help of medication. Unfortunately, at these times I stubbornly refuse all help due to the delusions I experience, and the law safeguarding my rights to refuse treatment prevents me from being given the help I need and would in my normal mind agree to.

"I hope that the law can be amended so that people like me can state our wishes freely while we are in a normal frame of mind and be assured that they will be followed in spite of our efforts to rescind them in times of crisis. These wishes, for me, would include the giving of short-term medication at the discretion of my appointed attorney or

substitute decision-maker, even in the face of my protestations and deluded arguments at that time.

"My past history is crucial to the doctor's decisions, so if he or she is in any doubt it should be mandatory that he or she consult with the family doctor. I know that in the past I have appeared capable in the eyes of several doctors, who as a result were reluctant to treat me, when actually I was in a complete state of delusion with my own irrational agendas that I was able to keep hidden.

"I am aware of the pleas of survivors of the mental health system who are attempting to affect a law that respects the rights of the individual to decide his or her treatment, and while I applaud this, I wish to ask that the law might be so defined to also include my rights to treatment when in this delusional, uncooperative state.

"I do not wish to be an anti-social member of society, nor a burden on the legal and health services. My case is quickly and easily stabilized with timely intervention. But the law as it stands blocks access to the aid I need in time of crisis. Could you please try to formulate a law that safeguards our rights to medical treatment. Thank you."

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**The Chair:** Thank you very much for your presentation. Mr Chiarelli.

**Mr Chiarelli:** Thank you very much for your submission. Once again you, together with a number of other people, have demonstrated that there are some serious gaps in the legislation. There are thousands of family members who have gone through that experience and a lot of individuals have ended up doing themselves a lot of harm, because they have not received the necessary medical attention.

I am looking for your opinion. I certainly hope that legal counsel and other members of the committee would consider amendments which would be imposed by regulation which would acknowledge a certain small number of mental illnesses such as schizophrenia and manic depression, where there are known experiences where people resist medical treatment when they should be having it and they are then freed. I wonder if perhaps there could be regulations which will say that either the Ministry of Health or an advisory board will define certain illnesses where the presumption is reversed. In other words, if there is a known experience or record with a particular individual with schizophrenia or manic depression, there would be a presumption of incapacity and a presumption of consent for specific purposes and short-term purposes so that these people would not do themselves harm.

I have heard a lot of people who are very concerned about the legislation as it exists now and as it is proposed. I wonder if you have any comments as to whether or not that might be an appropriate approach, where the onus would be reversed for people who have had a record of certain illnesses defined by regulation. It certainly would take a lot of pressure off the medical practitioners if they knew the onus was in favour of giving treatment rather than opposed to treatment.

**Witness A:** Yes. I would find that very satisfactory. That is really what I am asking for, that it is recognized

there is an illness and that we do not always have to start at base one, taking him in and deciding whether he is capable.

**Mr Chiarelli:** The one weakness of this, of course, would be the fact that it would not apply to first-time situations.

**Witness A:** I realize that.

**Mr Chiarelli:** That is a very significant gap. Perhaps people could put their minds to how that could be addressed. But it occurs many times in repeat situations with a small number of mental illnesses, and most particularly with young people as well, and the legislation has got to address that particular situation.

**Witness A:** Yes. I emphasized here short-term medication, because there was a tendency, which I think is not so now, to keep patients on this heavier medication that brings them down from the mania. It is a very unpleasant drug. I think there is a tendency now, once they have got them into normalcy, to try and withdraw them from that medication and maintain them on lithium, which at least for my son has no known side-effects.

**Mr Chiarelli:** I will be proposing amendments to cover that if the government does not and I am in the process of seeking some advice from medical practitioners who would be of some assistance in that area.

**Mr Poirier:** How much time do we have?

**The Chair:** A couple of minutes.

**Mr Poirier:** I looked at your recommendations and whatever, and obviously I am sure all of us are trying to put forward something that will be in the best interests of everybody.

Suppose your son decides not to go, to stay away from medical treatment or whatever, and you know that he needs it. What do you see as the mechanism to unite your son and the medical treatment he needs? How do you do it while protecting his rights? How would you see the law being able to do this?

**Witness A:** By having him appoint a power of attorney under the new legislation, or substitute decision-maker, write out what he would like under these circumstances, describe his past experience—he could even make it for a limited time that has to be renewable to safeguard his rights—and request that his wishes be carried out that he be given this.

**Mr Poirier:** In your first recommendation that I am considering here, I presume where you say the substitute decision-maker could be empowered to contribute opinions as to the person's capability, and such opinions must be taken into consideration by the health practitioners and the law—I try to imagine the real case situation.

If I were the substitute decision-maker and I were asked to give my opinion as to, "Yes, this is my son, and this is what I think you should do"—not being a medical authority, obviously you would have in hand some kind of information to back up your claim that your son has such-and-such a condition. I could never on my own initiative make an informed medical decision as to the nature of what would happen to my son. Somebody would have had to help me identify this. Maybe in the beginning I could

guess what it is, but after a while surely I would have an informed opinion based on medical records or medical evidence or whatever; surely not just my own.

In that first part of your recommendation, if the health practitioner came up to you and asked the substitute decision-maker, "Well, what's happening here?" surely you intended that to mean that you have some informed opinion here on a piece of paper, an official document that says—

**Witness A:** Yes.

**Mr Poirier:** I am sure there could be some situations where the person who is need of health services, in a situation where the family is not supportive or the substitute decision-maker is there for the wrong reason, could end up being on the short end of the stick. You admit that, I presume.

**Witness A:** Yes.

**Mr Poirier:** Obviously not in your case, but in the worst-case scenario where the rights of the individual may be threatened, we are trying to make sure the law that will be brought forward will plug as many of the loopholes as possible.

**Witness A:** Yes, of course.

**Mr Poirier:** So what would be the difference between the first and the second? I presume in the first recommendation, you would submit a medical decision based on the legal document that makes you the substitute decision-maker that would say: "This is the nature of the decision. This is the wish of our son. This is what he has mentioned, and if he has a downfall where he claims he doesn't need medication, there is what it says." But the opinion of the person's own medical practitioner, as in your recommendation 2, would not be at that point different from what you would show the initial health giver in number one.

**Witness A:** That is true.

**Mr Poirier:** Is that correct? Have I understood that well?

**Witness A:** Yes.

**Mr Poirier:** Okay. Thank you very much.

**Mr J. Wilson:** Just thinking of Mr Chiarelli's model, I do not really at this point think that would work, in terms of listing diseases for not the first but subsequent occurrences of difficulties or sickness.

I would like to ask, though, because you raise some excellent points that have been raised before, and I need a clarification for my own mind, perhaps from legal counsel. I guess the problem you raise, if you were to get guardianship of your son or power of attorney for personal care—as you say, when your son is presented to a physician who probably does not know him at all in the emergency room and he is deemed capable, he can then refuse treatment.

Mr Fram, perhaps you could tell us, first of all, that scenario over again. Second, where in that scenario is there any input from the parents?

1020

**Mr Fram:** In the bill or the group of bills before you, there is actually nothing that addresses the issue these parents have raised. In fact, he does become capable, and when he is capable, a guardianship order could not continue. Guardianship in those situations does not work. Powers of attorney for

personal care depend, in essence, on an assessment of incapacity.

We have a lot of bridges to cross. We have to somehow get the person to an assessor, and the problem of getting people to an assessor is that somewhere this right to coerce them at some stage of the illness has to exist. We have a citizen and somehow other people—the police, parents, friends—have to get the person to an assessor. There is no right given and it works.

The idea of power of attorney for personal care works for the elderly in facilities etc, but we now have a grown, adult person who does not want people to take him to an assessment. Then we have the central dilemma of a finding of incapacity. As pointed out, people with bipolar disorder appear competent; that is, given the ends that they are suggesting at the time they are manic, they can tell you how to get there. If they want 15 houses, they know how to go to real estate agents, arrange for tours of the houses and put a deposit down. It is a problem. There is a question of how you get a finding of incapacity to operate in the circumstances.

We have a number of great hurdles. We cannot, as a matter of law, simply choose people with bipolar disorders, or people who are diagnosed that way because there is a problem in diagnosis, and overpower them.

The issue of looking at some pre-validated power of attorney is one that has been raised. It is being raised by the Friends of Schizophrenics, and it is one we are looking at, but it does require a lot of coercion in the process, and the only source we can look to for authorization of use of such force by friends is the person himself or herself.

It is looking at those kinds of issues and the benefits versus the detriments that we are in the process of dealing with now.

**Mr J. Wilson:** Could you not, in a balance of rights—I mean, where necessary, the assessor, the physician, assesses the patient. What about a model where somebody assesses the parents or the friend who is trying to act on behalf of the patient? In that process, say you were to find that the parents are indeed loving parents, that there has been no history of abuse and that indeed what they are telling you is without question for the betterment of the patient. If that were found, is there not a way to have their opinion then weighted into the decision?

**Mr Fram:** I think that in the idea of identification, one of the notions—to take a perfect example, or a very simple example, getting out of the psychiatric field, if we are an alcoholic and we know we go mad if we start drinking, should we be able to tell our two best friends, “If you see me pick it up, pick me up bodily, carry me out of the bar and lock me in the barn until it passes”? Is that something we ought to be able to do in a document of our choice when we are sober?

That is the kind of notion: to give the recognition to somebody who knows us, knows our pattern of behaviour as a triggering device—our family physician—but to make sure that the document itself initially is voluntary; that is, that it is not coerced by family, that the condition under which it operates is clearly defined, that the people who

are to determine the existence of the condition are clearly defined and the limits of its operation are clearly defined, and yet authorize some degree of coercion. Taking me to the physician, taking me to whoever is the assessor are all things that are pre-authorized by the individual himself.

Of course, you have to recognize that this can be used if we have someone with a bipolar disorder. They can also say, “Take me to a monastery and not to a mental health facility,” or “Take me to the country.” So the document does not necessarily come to a result that the people who are suggesting it think is natural and automatic.

**Mr J. Wilson:** I think one of the problems with this legislation—it reminds me of the Charter of Rights and Freedoms—is that it is based on protection of the individual, and one of the debates we should have is whether there are groups rights involved in this.

**Mr Fram:** The charter, in fact, governs everything we are doing in this, and there is nothing, as lawmakers, that we can do to avoid it. It does say that we cannot choose schizophrenics and people with bipolar disorders and say, “There is a whole new regimen that takes away your rights up front.” So yes, everything we do here is governed by those central principles.

The challenge is, working within those principles, can we have an answer that meets their son’s needs? That is the difficult but challenging effort we have to make.

**Mr Winniger:** To follow up on what Mr Fram just explored, it seems to me that your suggestions are very good ones, and in most cases one would hope that the psychiatrist dealing with your son would be governed by these considerations.

The challenge comes when you want to legislate it. What you are asking for basically is a kind of waiver where your son could either express orally or indicate through the means of that letter that when his perception is clouded by the manic phase, if you will, he cannot make rational decisions about what treatment is appropriate. So nine times out of 10, I will grant you, it would be more appropriate, perhaps, to treat your son than not, because it would accord with his own wishes. It would be an authentic form of decision-making.

On the other hand, perhaps in one case out of 10, your son may not really want the treatment. He may have good reasons for not wanting the treatment. I am not talking about extreme examples like the last one—I do not know if you were in the room—where electroshock was given and the mother was convinced that it was appropriate. Let’s say the 10th time the psychiatrist indicates: “I’ve got this new wonder drug, clozapine, and it seems to be doing a marvellous job of curing schizophrenia. On the other hand, in one case out of 20 it causes severe side-effects which could be life-threatening.”

Your son, notwithstanding that he is in a manic phase, may have the capacity to say, “I don’t like these side-effects,” and yet he has signed a waiver and you are there in the presence of the psychiatrist saying: “Here’s his letter. This treatment sounds marvellous.” In that case your son’s wishes, possibly quite rationally arrived at, would have been overridden. I think there is a very fine balancing. I would

hope that our legislation can achieve that balance, but your situation is certainly a problematic one.

1030

**Witness B:** I just want to emphasize a point here. I realize we are talking about a very special case in the case of our son. We are using the term "mania," when I think it has to be understood that from mania you can slip into psychosis. This is a state of mind in which you are totally living in a deluded world. It is to protect our son who in his rational mind realizes that this is what happens, that we want the legislation to meet his needs and his wishes when he is in his rational mind.

When he is in a state of psychosis he is in another world. It is at that time that we need to fine-tune this legislation so that the highly specific instances such as for example our son's are taken care of. That is the thrust of our very special request, that the legislation take this into account.

**Mr Malkowski:** Thank you for your presentation today. You were talking about your son maybe being able to express his wishes in advance of certain kinds of treatments. I agree that he should have the ability to do that. We have had some presenters, such as psychiatric survivors, come forward. Some of them have been misdiagnosed as schizophrenics and they want the right to refuse treatment, but they do not have that. I wonder how we can match their needs. Do you agree that we should have some types of protection for those certain groups of psychiatric survivors who have already been misdiagnosed and have suffered from wrong treatments? Should we have specific protection in the legislation for those groups?

**Witness B:** Absolutely; no question whatsoever.

**Witness A:** Of course. I do not envy you the job of doing it, but of course they should.

**Mr Wessenger:** I am interested in your suggestions. It appears to me you are suggesting that in the criteria in determining capacity, right now many times important criteria, such as the knowledge that you have about your son, are not taken into account; second, the nature of his illness, and third, the evidence of his own medical practitioner. You would like to see those taken into account in terms of capacity and you would like to make sure the system did that, is that correct?

**Witness A:** Yes.

**Mr Wessenger:** To me that seems a very reasonable process.

**Witness A:** It does, but the law does not allow that at the moment.

**Mr Wessenger:** I would think that in a proper assessment it ought to be taken account of.

The other thing I am going to perhaps suggest to you is that a lot of the problem is the timing and speed of the process. Is that fair? Is that one of your concerns?

**Witness A:** Yes.

**Mr Wessenger:** I suppose you would say to us that if there is any way we can work to expedite the process, particularly with respect to situations like your son's disease, that would be something that should be looked at?

**Witness A:** Absolutely, yes.

**Mr Wessenger:** That is not changing the law. You might just give some more priority to determining capacity with people having diseases such as bipolar. It is certainly something that could be looked into. I think it is an interesting concept. I would like to thank you.

**Witness B:** In our own son's case it is extremely dramatic that he can slip or slide into psychosis, and upon receiving the appropriate medication, within 48 hours he will come back to sanity and say, "Thank you, mom and dad; I'm back," that sort of thing. This has sometimes been relayed to us by a long-distance phone call from Kingston or somewhere when driving along the 401 he has suddenly woken up.

I emphasize the short-term treatment, the incredible effectiveness of this in our case. It is access to that which is sometimes jeopardized by ambiguous legislation and rules. We have had to do all sorts of terrible things, painful things, to have him arrested by the police and get the necessary form under very unpleasant circumstances. We are talking about short-term treatment with drugs in the case of our own son.

**Witness A:** I should add that at the beginning, the first time, we were very anti-drug people. The first time he had one of these episodes at home we decided not to give him medication. We decided we were going to see it through. We were going to let him ride the mania and we thought normalcy would come back. This was going on for six weeks of no sleep. We are going crazy; dangerous things happening. In the end we got him in. We had to. We do know that without this intervention it is not just a matter of him coming down as he does when he is on the medication.

**The Chair:** Thank you, Mr Wessenger. On behalf of the committee, I would like to thank you, as concerned parents, for coming and giving your presentation this morning.

#### FAMILY ASSOCIATION OF MENTAL HEALTH IN ETOBICOKE

**The Chair:** I would like to call forward our next presenter, from the Family Association of Mental Health in Etobicoke. Could you please identify yourself for the record and then proceed.

**Mr Sande:** My name is Bill Sande. I am chairman of FAME. My associate is Judy Wallace, who is the coordinator for FAME. I would like to make a few introductory remarks, sort of an overview of the situation as I see it, and let Judy speak to the details of the legislation that is proposed.

In our association I would say families are unanimous in one objective, and that is to see their ill relative well. They would like to see the person well, participating in society up to his or her capability with an opportunity for a reasonable quality of life. Our membership is approximately 150 families. We have been organized since 1989 and last year we were incorporated. One common observation I make about our membership is that most of the membership is middle-aged to elderly. They are people who have been dealing with a problem for an extensive period.

My own personal experience is 12 years of living with mental illness. I can say, the same as the family before us,

that it is a draining experience and results in a substantial loss of productivity for those closely tied as care givers. People never seem to realize or take into account this loss of productivity to society, not only in the ill person but in the members of the family who are the care givers as well.

The Mental Health Act has presented many impediments to a family. The ill persons must be deemed dangerous to themselves or others prior to receiving treatment. Another obstacle that families face is one of confidentiality. Families may be excluded from treatment information and upon discharge from hospital receive no counselling regarding the aftercare of the ill individual.

The Mental Health Act requires that families avail themselves quite often of legal advice when they are first confronted with a mental illness. Patients, and rightly so, have access to very competent, expert legal aid whereas families generally have to approach their family lawyer, who is not well versed in Mental Health Act matters. Now we have more legislation added to the Mental Health Act and we are creating what I would describe as a bit of a legal minefield for families to try to really understand what they may do and what they may not do with respect to the treatment of their ill relative.

Families and patients I have spoken to, and I underline "patients" as well, emphasize to me the need for continuing treatment, not necessarily to stop treatment. An awful lot of these people rely on treatment for their continuing functioning and day-to-day wellbeing. I have observed first hand the treatment given to mentally ill patients. I have seen and witnessed the abuse of such treatment—excessive dosage of neuroleptic drugs that render the patient extremely docile.

Significant side reactions attend those drugs. I have seen misdiagnosis, just as was indicated by the witness speaking previously, where people who have been sexually abused early in their life have been treated as schizophrenics when they are not schizophrenics. I can understand their resistance to taking neuroleptic drugs or electric shock therapy. In my case, I have a son who had a massive head injury 12 years ago and has been treated for schizophrenia for 12 years and is now being diagnosed as having a head injury. I am a moderate person here expressing a moderate viewpoint on behalf of the law and the laws as we see them.

1040

In my previous work experience I had considerable dealings with large construction projects. When I started my career the agreement consisted of a handshake with the contractor. Ultimately the contractor's legal document may be signed prior to the completion of the job. Everything was done in good faith. As we grew and went out for bids on larger and larger jobs we would have five or six contracts to read, trying to understand what our responsibilities were and what those of the contractor were. A thought dawned on me: Would it not be wonderful if we had our own contract, seeing as how we had a whole battery of lawyers. Instead of us reading six contracts we would let the contractors read our contracts, because we would know what was in that contract—a very, very simple thought, and that was implemented.

You say what relevance is this to this kind of proceeding? The question I would like to ask is one with process: Who initiates the process of such legislation? Who hammers out the details? Who are the people present when all these legal arrangements are made? I know one thing for sure, that parents are not. Parents are not present when the drafting is taking place. We are told we are part of the problem. I understand that. We are the care givers, the place of last resort. We are the taxpayers. Does the legislation meet our needs or our objectives?

The bulk of our people do not understand these laws as they struggle with serious behavioural episodes and search for treatment. They are frustrated by a lack of service facilities and by a lack of their own personal training and they are now frustrated by more and more laws. As a family group, all we ask for is a level playing field. We do not want to be adversarial. We want input into the beginning of the process, not at the end of it. We want to reduce stress on our families. We want our ill relation well and fully productive in society, a taxpayer and not a tax drain.

Those are my general comments, and I will turn it over to Judy Wallace for her specific comments.

**Ms Wallace:** In outlining FAME's concerns about the pending legislation, Bills 74, 108, 109 and 110, it is important to provide an overview of our organization. FAME is a locally based family group in Etobicoke that includes the entire family. FAME is open to families regardless of the diagnosis of their ill relative. The families who are members of FAME continue to have active involvement with and provide active support to their ill family member. That support may take the form of residential care, family support, social support, advocacy, emergency care or any combination.

FAME is aware that there are many suffering from mental illnesses who depend on their medication and treatment, and access to hospitalization when necessary. However, there are also medications and traditional medical treatments that preclude positive results for some conditions and situations. Mental illness is a broad category that includes some conditions that can be attributed to life circumstances, as well as those that fall more clearly into the category of illness or chronic condition. For those who feel that the existing mental health system has been of some help despite its shortcomings, protection is important, but treatment is equally important.

FAME supports and endorses research to determine causes of mental illness in the hope that this will lead to the development of treatments that are effective in symptom control without being intrusive. As families, each FAME member hopes for the day when their ill relative is able to maximize his or her potential and provide for himself a reasonable quality of life.

The fundamental goal of FAME is to reduce stress on families. This can best be done through treatment, programs and care that support and encourage each of the ill relatives to be as well as possible for as long as possible. This also includes planning for those times on the continuum when illness predominates.

In discussing Bill 74, the purpose of this bill does seem laudable. However, there are assumptions made that may not reflect an accurate assessment of existing situations.

The bill assumes that an adversarial situation always exists between mental health survivors and the mental health system and between the mental health survivors and their families. Although this may be the case in some individual situations, it does not reflect what many families and their ill relatives feel. The enactment of this legislation to protect the few disregards the needs of the many.

The role of the advocate as it is currently enacted is a narrow, legalistic presentation of a complex situation. If the advocates were instructed and directed to assist the individual in assessing the whole situation and the long-term ramifications of a decision, then their role would be seen as responsible and sensible. However, nowhere in the existing situation with advocates in the provincial hospitals or in this proposed legislation is there any indication that the advocate's role is to present a balanced view of the existing situation. One can only assume that the advocates, with the current job description, will continue to fulfil the role in the traditional way. That is not to say that individual advocates do not act responsibly, however.

When explaining the individual's rights, the advocate should also outline the individual's responsibilities. Those responsibilities include a realistic consideration of the consequences of any decision—to accept or reject treatment or any part of treatment, to remain in hospital or to leave, to accept responsibility for accommodation and basic needs.

The Advocacy Commission is composed entirely of survivors, with no consideration of the advocacy needs of families. Although there are groups like FAME that do advocate both individually and systemically for and with families, with the increasingly legalistic process involved in obtaining mental health services, an advocate mandated by the government to address family needs, support family organizations and represent a family perspective is critical. Families represent the largest single group of care givers. They are unpaid, expected to perform their jobs prior to any training and given little access to training and are available when no one else is.

The bill states that the role of the advocate is "to acknowledge, encourage and enhance individual, family and community support for the security and wellbeing of vulnerable persons." Would this not be more easily accomplished if there were family representation on the Advocacy Commission?

1050

Families, like survivors, need their own groups to work exclusively for their needs and issues. But like the survivors, their input and access to the system needs official support. Families also need the recognition and protection in law that ensures that they will not be abused by those professionals involved with their ill loved one. They also need a method of recourse that protects their ill relative from retaliation.

Bill 108: This bill clearly outlines the requirements for a judgement of capacity that takes into account the appreciation of the consequences of action or lack of action. However, it does not provide any guidelines or qualifications for that appreciation.

For instance, if an individual whose behaviour would indicate that he or she is ill states that he or she understands

that by refusing admittance to hospital he or she will have no accommodation and in December that is all right, is that an appreciation of consequences or a disregard?

Although the bill clearly outlines power of attorney and guardianship for property and personal care, it is unclear whether these functions would fall under the same jurisdiction or whether they would fall to different jurisdictions or different people. It is important to provide a process that would permit both possibilities, as in many instances of mental illness, control over fiscal matters can become a very contentious issue best left to the control of strangers, whereas personal care often needs the historical connectedness of family, who will remain involved.

Bill 109: Consent to treatment as outlined in the Mental Health Act is very similar to what is being proposed in this act. The difficulties experienced by those implementing the existing legislation seems to have had no impact on the development of Bill 109. In many instances of psychosis, the ill individual is capable of incorporating the assessment procedure into his delusional system, thus appearing quite rational. If the exhibiting behaviour were placed in context—ie, psychosocial history from previous assessments, if existing, file notes or reports from physicians of record and/or family—then a more accurate assessment could be made by the attending physician.

Although informed consent is always the preferred methodology, it is not always the feasible option. In the proposed bill, the provision for determining capacity, "able to understand the information that is relevant to making a decision concerning the treatment and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision," does not consider that acceptance of a poor consequence may be a reflection of illness rather than a real understanding. Again, there is no benchmark to measure an individual's understanding of a situation. In other words, is this the kind of decision this individual would make in normal circumstances?

If an individual, in a state of rational thinking, sets out the course of treatment he or she feels is necessary, excluding the treatment that is not wanted, and appoints an attorney under the power of attorney, that individual should feel safe in those decision. However, what safeguards are there to ensure that the "rational decision" will be honoured if that same individual, in a different state of mind, expresses a desire to revoke the power of attorney?

Bill 110: This bill is clearly a housekeeping bill intended to amend a vast range of legislation so it is all consistent with the preceding three bills. The question arises as to how all those who worked within the range of legislation from the Drainage Act to the Mental Health Act will be aware of the implications of the proposed changes. Will materials be developed for those who are not trained in jurisprudence that will explain in clear, simple language what the bills mean, who is affected and how these bills affect other bills?

Finally, what provisions are being made to assist the medical profession to accept these changes as a routine part of their work? Those who have encountered the response to the Mental Health Act are aware that many psychiatrists adopt a stance of narrow, legalistic interpretation that

paralleled "work to rule." Further legal requirements may have the effect of reducing the possibility of treatment, even for those who are requesting help in a clear manner.

The basis of this proposed legislation is clear, as both a change in philosophy and a response to court decisions. However, for the families, individuals and professionals who will have to work with yet another set of laws, the mental health system is beginning to feel like an onion. For each layer that is peeled away, there is yet another layer to peel. A system that has become excessively complex to access has the effect of reducing access as well as ensuring protection. Is there not a way to provide a comprehensive piece of legislation that protects and provides access without needing a law degree to get help?

**The Chair:** Thank you very much for your presentation.

**Mr Chiarelli:** Thank you very much for your submission. A lot of the comments you have made have been common to other presenters who have been here, both in the case of advocacy and the other more technical legislation. I share some of the concerns you have expressed in this legislation, and my concern is that the government appears to be in a legislative straitjacket. They are taking the traditional approach of going through first reading, second reading and coming into a committee, and then trying to presumably amend the legislation to take into account a lot of the concerns that have come forward.

In this particular instance, there is nothing approaching a consensus on the part of the groups that have come in here. We have had groups such as the College of Physicians and Surgeons, we have had esteemed presenters such as Dr Lowy and we have had people who are working in the field such as yourselves express very serious concerns about the legislation, and one of the overriding concerns is that there is no consensus on how to approach this legislation or how to implement this legislation.

I think it is important that there be a consensus with this legislation, because it affects so many people personally and emotionally and so many people working in the field. I am just wondering if you are of the opinion that we would come up with a better piece of legislation and a better solution if we were not dealing with live legislation. If we had a draft bill that could be worked and reintroduced at a later date, do you feel more people would be able to respond in a positive way, such as groups of parents or what have you? I am concerned about the shotgun approach of the legislation, that we are in committee, we are going to go to clause-by-clause and then it is going back in the House for third reading.

My assessment is that clause-by-clause is not going to be able to address this legislation, because there are too many concerns, first, and second, there is nothing approaching a consensus on legislation that must be dealt with by the community at large. Do you have any comments on that?

**Ms Wallace:** I would tend to agree with you on that. I mean, clause by clause it is fairly easy to say, "Yes, that's okay, that's okay, that's okay." It is when it all fits together and you are looking at this package that people are going to have to work with and understand that it becomes a very complex issue.

If it went to a situation where there were affected parties involved in hammering out something from new draft legislation so that you had representatives from all the groups—from families, from survivors, from physicians, from social workers—in a balanced kind of way, as well as obviously people from the Legislature, you might be able to find that consensus. You might be able to find where the balance would be. I do not think these bills provide that balance. I think the intent was very positive, but I think the outcome is going to be miserable.

**Mr Chiarelli:** But the government sees these proceedings as leading to improved, refined legislation. Do you have any confidence level that the legislation as it is presently constructed can be made appropriate by refining the particular sections by amendments, or do you think there needs to be a broader consensus before we go to specific legislation?

**Mr Sande:** I guess I would say there needs to be a broader consensus. That would be my reaction. I do not know what Judy's opinion is.

**Ms Wallace:** Yes.

**Mr J. Wilson:** Thank you for your presentation. When Mr Chiarelli talks about a legislative straitjacket, the way I see it, and the reason that with the last presenters I asked legal counsel about the charter of rights, is that I suspect we know from the discussions we have had both in committee in the last week and in the many meetings each of the caucuses have had with groups on the side that the consensus would be that you have to strike a balance between the rights of the family—the group, as it were—and the individual. The legislative straitjacket I think this government is in—and something you can thank Mr Trudeau for—is the Charter of Rights and Freedoms.

You do not have any rights. You are the family. You are the group. The charter is designed, and all legislation must conform, to protect the rights of the individual, and the individual is supreme in our society, contrary to my party's philosophy. That is the way society has gone, and we have seen a very legalistic world since 1981-82 when the charter was introduced. So in spite of the fact we all want to see a balance, I do not know how you can do it.

I would ask the government, though, whichever parliamentary assistant, whether any tinkering has been done with the definition of "capacity." I see every other link that one has to go through under this legislation as weak. But the strong one is that it seems to hinge on the terms "capacity" and "incapacity."

Probably the only way to give some rights to the family would be to make it easier to deem someone incapable; hence power of attorney for personal care stays in effect or guardianship stays in effect. One assumes the family at an earlier point would appear before the court under this legislation and acquire those powers. I may be a little crazy, Mr Fram, but I am fishing here.

1100

**Mr Fram:** Just to address the question, we have given a lot of thought to the notion of capacity. But it is quite interesting that even then you have the Community Living people who spoke to us last week who essentially deny

incapacity exists. You will see other groups who in fact want to decrease the level of capacity for other purposes. It becomes a very challenging situation.

**Mr J. Wilson:** That was very helpful, Mr Fram, but honest.

**Ms Wallace:** Could I make a comment on this? One of the things I feel very strongly about in this is that yes, we have legislated rights until we can wallpaper with them. But we have left out the underlying concomitant side of that, which is responsibility. If you have a right you then must have a responsibility that goes with it.

**Mr J. Wilson:** I did see that in your brief and it is a very good point. I think you suggested the advocate would have to explain the parallel responsibilities: that you have some responsibility to society if you take decision X. You could affect Y.

**Ms Wallace:** And responsibility to yourself.

**Mr J. Wilson:** That is a good point. I suspect the government's answer would be, "Well, that would be included in the training of an advocate." The legislation does not address what an advocate is really to learn or what the regulations will be. Who are these people who are interfering in your life? I do not know. I suspect from some of the people who have appeared before us who tell us they are going to be hired as advocates, or hope to be, that they are people coming from very diverse backgrounds, not necessarily from any particular professional field.

**Mr Malkowski:** Thank you for your presentation. It was very helpful. One interesting thing you mentioned was that between the mental health survivors and the system it was adversarial and perhaps the survivors had an adversarial approach between the survivors and the family. You said we looked at the needs of the few to protect the few and ignored the majority, correct? I am just wondering, you have not mentioned anything about the family, and the struggle between the system.

Persons within the disabled community said that they have a struggle with some of their family members. I think you are right. We do need to develop a balance. I am just curious. Do you agree about finding a protection for the vulnerable person but people who have already experienced abuse from the family, or do you think that is not a common situation?

**Ms Wallace:** I think in situations where there is abuse from a family—and that certainly has happened in a lot of cases obviously; the number of cases of sexual abuse clearly come from some family connection—those families do not tend to still be involved. The survivors have removed themselves from that situation and created a different kind of network.

I think we are talking about adults who are in a situation where they are still affiliated with their families and so have rights to associate with and name people who make sense to them. With an abusive family it would make sense that they would not name that person when they were in a good state of mind as someone to be their power of attorney or guardian. I think what we end up confusing is the sense that if somebody is in a disabled situation they are stuck only with people who are abusive to them. There

may be situations of that, I am not denying that, but I think that is not in a large majority of cases, particularly in an urban setting. That may be more true in rural settings where resources are fewer. But I think the families that remain involved tend to be families who care and who will put up with things over a very long haul.

**Mr Malkowski:** This legislation, the Advocacy Act, I think clearly supports the family, but to support and protect the vulnerable person is the goal. You are saying the legislation would not help the family. So you are in agreement, then, that legislation should help the family where their goal is to protect the vulnerable person, correct?

**Ms Wallace:** Yes. The existing situation is that the families are the care givers. They are given no indication and in a lot of cases many of the medical practitioners throw up the Mental Health Act as it exists now and scream, "We can't talk to you because of confidentiality," when maybe all a family wants to know is what the side effects of medication are. Yet they are isolated from basic information now. This is going to make it even worse.

There was an instance last week where a family member was very concerned because her son had walked out of hospital after having had four suicide attempts in one day. We were calling to find out if they had reported him missing to the police. That strikes me as a pretty simple request for information. The head nurse on the floor of that hospital said, "I am not permitted to even tell you I recognize the name." I think we are in a position where the letter of the law has transcended the spirit to the point that that young man is at serious risk because nobody will even talk about whether he was or was not there or that they have ever heard of him. Where does that leave the family in trying to help when someone is out on the street in a psychotic state?

**Ms Carter:** Thank you for your thoughtful presentation. My points are similar to Mr Malkowski's concerning Bill 74. I am concerned that you think the bill assumes an adversarial situation between the mental health survivor and the family. Of course the prime purpose of the advocate is to listen to the individuals and to empower them. Of course a lot of people do not have family or friends and really have to have that. I agree with you that in most cases the family is supportive and in some cases the advocate may help the patient and the family collectively, for example, as happens now. There are advocates in mental health institutions and they can inform the family sometimes when there are problems that they can then follow up on.

There are a few cases where the family is part of the problem and you mentioned that sometimes a family can be abusive. Sometimes I think the family can be part of the problem in a much more subtle way. I think it is these rather complex cases where the need for an advocate to go straight to the patient is of vital importance. I hope you will see that that is something we are trying to do in this act: to make sure that person is listened to and the circumstances are fully gone into. As far as representation goes, it is hard when you are setting up boards and commissions and so on to include all the people who should have a voice. I believe on the Fram commission there were 24 people representing different aspects of the problem, and

even then there can be complaints that not enough people are being represented there.

1110

**Mr Wessenger:** It would seem to me that the Consent to Treatment Act is in effect increasing the role of the family. First of all, the preferential persons who have the right to consent to treatment are the family members unless there is a power of attorney, so I think that would assist the situation.

Second, the Consent to Treatment Act does permit a family member, once a finding of incapacity is made, to admit the patient to treatment if the patient does not object, so I think that also gives you a role. Once, of course, the incapacity is found you have the right to informed consent as a family member, as the preferential person, so I think really the Consent to Treatment Act strengthens the role of the family in this regard.

**Ms Wallace:** It provides on one side without supporting on the other side because there is no change in the way things are currently done. If a family has the authority to consent to treatment on someone's behalf because they have that in writing or it is an assumption because it is a close family member but they do not then have the freedom to know what the treatment is or what the medication is or what is proposed, where does that leave them?

**Mr Wessenger:** They have the right. Under the new act they will have the right to be informed.

**Ms Wallace:** It is not that clear.

**Mr Wessenger:** I think it is quite clear. Informed consent has to be to all treatment. The substitute decision-maker has to give informed consent; otherwise it is not a valid consent.

**Ms Wallace:** It is going to be a very interesting prospect teaching this to the entire medical profession.

**Mr Wessenger:** I think perhaps if you would just look at section 18 of the Consent to Treatment Act that would clarify it for you.

**Ms Wallace:** Yes. Is that going to amend that section in the Mental Health Act which deals with confidentiality which puts parents in a position, as the case I cited, of not even being able to find out from the medical profession whether in fact their relative was in a hospital when he disappeared?

**Mr Wessenger:** I understand this will override the Mental Health Act provision.

**The Chair:** Ms Wallace and Mr Sande, on behalf of the committee I would like to thank you for taking time out this morning to come and give us your presentation.

**Ms Wallace:** Thank you.

#### INTEGRATION ACTION GROUP OF ONTARIO

**The Chair:** I would like to call forward our next presenters from the Integration Action Group of Ontario. Good morning. Could you please identify yourselves for the record and then proceed.

**Mrs Troyer:** I am Katherine Troyer.

**Mr Nathwani:** My name is Rashmi Nathwani. I am a member of the board of directors and a parent.

**Mrs Troyer:** I am past president of the Integration Action Group.

**The Chair:** Please proceed.

**Mrs Troyer:** The Integration Action Group is an action-oriented association of parents, educators and concerned citizens whose goals are to help families achieve integration for their children and to advocate for attitudes, practices, policies and laws that promote integration in education and in the community.

We believe the Advocacy Act in principle is a good one. The act empowers the advocate but does nothing to enable the vulnerable person. Giving a person an advocate does not necessarily make them less vulnerable. My son Matthew Lutes had a mother who treasured him, and he was still involved in the Grange commission in 1981. Having an advocate who always was with him did not prevent him from being vulnerable. My son would have been less vulnerable if he had the right to fair and equal treatment in Ontario. This still does not exist even in 1992.

My son Mark was born in 1983 and was also disabled. Being disabled did not make him vulnerable; society did. They consistently tried to set their standards of quality of life on him and he just could not conform. As his family we not only accepted his uniqueness; we celebrated it—but not without its price. The medical field was appalling and the education system was inaccessible. Nothing came without an incredible fight. On numerous occasions Mark was signed out of hospital for his own safety. There is no justifying non-treatment of any human being.

If you truly want to make people less vulnerable then enforce the Constitution that we hold so sacred in this country.

It is our belief that there is a distinct difference between an advocate and a social work model. We would not want to see a social work model used in setting up the advocacy office.

We believe there will not be enough advocates to go around. If that is the case, their job may become one of crisis intervention rather than empowerment. It is our strong belief that we would like to see the advocacy system become properly established without exceptional demands for rights advice created by the Substitute Decisions Act and the Consent to Treatment Act.

With respect to Bill 109, we believe in the principle that persons aged 16 and over are presumed to be capable. We have some concerns around the access of an advocate. If a person who is over 16 can access an advocate, if he is seen as vulnerable in a treatment situation, we feel a child should be able to access an advocate under the same situation.

Only medical considerations are appropriate in making medical decisions, not consideration of whether the individual will be developmentally disabled.

The Integration Action Group cannot accept or condone varied commitment to anyone.

Guardianship by definition removes a person's decision-making rights and vests them in someone else. The underlying purpose of guardianship is, and always has been, to make legal provisions for the care, supervision and control of the property and of the person of those people who are

considered by others not to be capable of making decisions for themselves. We do not believe anyone should be subjected to this fate.

Deprived of the right to make choices, we are nonentities, non-persons whose lives are controlled by the choices of others. It is our belief that any new law should respect a person's right to take risks, as this is closely related to quality of life. We feel very strongly that taking away all risks from a person's life is destructive and leaves him with little purpose. Risks can exist and can be minimized with the help of family and friends. When the risks seriously jeopardize the safety of that person or others, a number of supports need to be in place, but the law should always be a last resort.

We believe some alternatives to guardianship are:

Parents, families and others can play a major role by encouraging and enabling the person with a disability to make his or her own decision. This recognizes that the labelled person is first a person with ability. For example, decisions about the use of money can be encouraged by using a joint bank account until the individual can manage an account of his or her own. The more independence we promote, the less the person will need to depend on others.

Personal support groups can be developed and maintained around the person. This becomes especially important when family support begins to erode or is simply not present. A caring group of people, including other family members, can provide ongoing support.

Ways of making individual advocates available to people who are labelled can be explored. Again, an advocate's role is one of support and assistance rather than substitute decision-making. Preferably, an advocate will be non-paid and committed to ensuring the person with a disability has authority over his or her own life.

We have also included a book that we released at the end of August called *Sharing the Vision* and we encourage you to read it.

**The Chair:** Thank you very much.

**Mr Chiarelli:** Thank you very much for your brief. I have a couple of questions to basically narrow down your concerns a bit more relative to the legislation. On page 6 you indicated, "We believe some alternatives to guardianship are." Are you suggesting that the legislation be amended to incorporate these three examples?

**Mrs Troyer:** Yes.

**Mr Chiarelli:** Are you suggesting that the guardianship provisions, as written, are inappropriate or that there should just be more alternatives? Maybe you could be a little more specific in terms of assisting the committee to understand exactly what you want.

**Mrs Troyer:** We believe that guardianship is inappropriate for disabled people. We have made people with disabilities vulnerable by segregating them and keeping them out of the community. We have realized that in our trying to bring people back into the community now. Subjecting them to guardianship would be a step backwards.

**Mr Chiarelli:** Is there some other model you would suggest of partnership between family or friends and a disabled person other than guardianship?

**Mrs Troyer:** There is the Joshua committee that has been set up around Judith Snow. There is Circle of Friends. There are things that are in the community that would enable people to be able to make decisions with support. Our suggestion is that we use every other means. You cannot just say because a person is mentally incompetent to make life or death decisions that they lose all their rights.

**Mr Chiarelli:** Unfortunately, a lot of people look at this area in legalistic terms. There are going to be people who have to deal with the disabled person, who are going to want to know whether that person has capacity or authority to enter into contracts or do various things or make certain commitments for themselves, whether it be medical treatment or living accommodations or what have you. It is important that you try to explain to the committee some sort of legal framework or context that this partnership could be placed in.

1120

**Mrs Troyer:** The partnership could be placed in with the advocacy role in most cases, and the advocate role exists in a lot of areas in the community already. The Ontario Association for Children with Learning Disabilities does it. Integration Action Group does it. There is a lot of support for disabled people in terms of advocacy in the community, and the advocate role would be that. We make decisions with support in normal situations. The disabled person should have that same right and not have those rights revoked only because they need assistance to make that.

**Mr Chiarelli:** Are you saying the present advocacy legislation as drafted is inadequate and you would prefer not to see it pass as is?

**Mrs Troyer:** No, that is not what we are saying.

**Mr Chiarelli:** It is a good first step, is that what you are saying?

**Mrs Troyer:** It is a good first step. What we are saying is, implement the Advocacy Act first and get that rolling before you bring in the other two bills, because the advocates are not going to be able to do their job with all three at once.

**Mr Chiarelli:** You want to defer enactment of the other legislation.

**Mrs Troyer:** Yes.

**Mr Chiarelli:** Do you agree with the terms of the other legislation, other than timing?

**Mrs Troyer:** No, not entirely.

**Mr Chiarelli:** You disagree with the substance of the other legislation as well.

**Mrs Troyer:** Yes.

**Mr Nathwani:** If I can just elaborate on the comments Kathy has made, in the first instance, on the guardianship act, we would prefer to see no act at all, just to be very clear about fundamentals, and certainly we find provisions of the Mental Health Act repugnant. In the event that you have to proceed with it, then there are significant provisions of it that need to be ameliorated. Our comments in the legalistic sense would be more akin to what the Advocacy Resource Centre for the Handicapped would present. I am

not a lawyer, but I am very clear at least. I want to make sure I answered that part of your question.

**Mr Poirier:** On page 5, again, obviously your very sensitive point about guardianship, at the bottom it says, "When the risks seriously jeopardize the safety of that person or others a number of supports need to be in place, but the law should always be used as a last resort." Is that telling me, from what I think I read, that if you are going to be using it as a resort, there must be some last resorts where you need a law where guardianship, whether we want to or not or by lack of other choices, would be needed, or what?

**Mrs Troyer:** We recognize that the system does fail, but we are not saying that because the system has lapsed, that in law everyone should have a guardianship. We recognize the vulnerability is there, but we are saying there should be lots of other things implemented before you look at a guardianship. I mean, guardianship should be last resort; there should be nothing else; everything else in the system has failed.

**Mr Poirier:** Granted, but you recognize that if other options are tried there may be some specific occasions where you come down to that last choice.

**Mrs Troyer:** Yes.

**Mr Nathwani:** Can you give me an example?

**Mr Poirier:** No. I was going to ask you that.

**Mr Nathwani:** Again on a fundamental plane, I am talking, say, about schizophrenics, because I have heard a lot in the press about it. I have a son who is 16 who has been on medication. There are times when medication will ameliorate their behaviour, but behaviour is a way that we in the outside world see them. Medication is given to prevent them from humming or rocking. Let's think about this. If a schizophrenic rightly or wrongly chooses not to accept medication, I do not think the law should intervene and say, "You will take medication" even on a call of last resort. I am being very clear on a fundamental plane. What we are saying is that if you do have to put something in—because we recognize there is a considerable lobby out there and considerable feelings among a lot of caring parents. The problem is not with the disabled person, the problem is with us in not trying to understand what they want, especially if they are non-verbal.

Let me add one last thing. Just recently we have seen discussion about facilitated communication. Unfortunately, we have only seen a five-minute clip on the CBC. I have read a little bit more about it. I have a son who has some autistic tendencies. I can tell you that when communication is facilitated with non-verbal people—they have never spoken—the first thing they talk about is not, "Can I have a cookie or oranges?" They talk about their deeper needs, "Why can I not go to a regular school?" or "Can I play with the other kids?"

The reason I am bringing this kind of anecdotal stuff to you is that I really have not seen an example, even with people with deep core needs, where you have to have intervention. Conversely, I can give you examples where treatment has been misapplied and people have been harmed for decades by it. The choice should be theirs. If

you cannot get through to them, find other means of communicating with them, but do not enforce the law there. That is a fundamentally strong, radical view, but I am very clear about it.

**Mr J. Wilson:** Thank you for your presentation. I would agree. Last Friday, we had the former public guardian of Alberta also tell us that guardianship should be the very last resort.

Along the lines of Mr Poirier's questioning, in the case of schizophrenia you said the law should not intervene. I do not see it as the law intervening when someone is trying to make treatment decisions that are deemed by a number of people to be best for that individual, whether it be a personal care decision or a treatment decision. When the guardian is making that decision, it is people intervening, it is not the law.

I know many people who benefit from treatment. There is case of schizophrenia in someone very close to me. I can tell you that when they are incapable, I do not think it is my understanding of that person that is impaired; I think the person needs help. It is a chemical imbalance in the brain and some therapies do appear to work. I do not think it is my perception of the situation.

**Mr Nathwani:** I am not denying that therapy is helpful. All I am saying is do not let the medical profession make that determination, because de facto that is how it works. The advocate should inform the person, but if the person refuses to take medication, the doctor should not be allowed—it becomes a little bit more difficult when it comes to close family. I trust family and friends more than I would trust a doctor. A doctor should never have that right at all.

Second, my son benefits from medication, I believe that, but if he does not believe it and he wants to pull the plug, I will honour it. It will be painful to me, but I will honour it.

**Mrs Troyer:** I think you are evading one real important issue. In the Grange commission, as parents, we never had the choice and my child never had a choice. Someone else made that choice for us and that was wrong. Nothing in any of this legislation addresses that. That risk is there. What happened at the Hospital for Sick Children happens all the time. None of this legislation is even going to address that issue, and the issue is the value of human life. When we address that and we say that disability has no bearing on whether a person gets treatment or does not get treatment—you have treatment by right and that is it—we can stop this insanity. You are having mass murders in Ontario and no one is taking responsibility or dealing with it.

1130

I adopted a little boy who has Down's syndrome two years ago, and in three instances in two years he has been at risk and been refused care because of his disability. That is crap. I will not tolerate it. That is my child.

If he had died in those three instances they would have said he had died of Down's syndrome, and Down's syndrome does not kill you. Neglect does and people's ignorance does. Address that.

**Mr J. Wilson:** I agree with you. I have a first cousin that has Down's syndrome and I notice in your book you

mention that the first reaction of the doctors when the child is born is just let the child go. My aunt to this day—my cousin is 33 years old now—still cries when she tells the story. There is some education there, obviously, needed for the medical profession.

**Mrs Troyer:** I think it goes beyond education.

**Mr J. Wilson:** It is education because—a startling statistic last week was that the number of abortions for people 15 to 19 is twice the number of live and still births in Ontario. If I am a doctor trying to reflect the values of society, I may say let your child go. Obviously twice as many people are making that type of value judgement. As politicians, we are here and we are told the Reform Party is popular because they are doing what the people want. If we did what the people wanted every day, you would have an even more screwed up society than it is. We have to balance these things with comments that you have made that I think are very important and all the other rights that are prevailing upon people these days.

**Mrs Troyer:** Without the right to life, the other rights are irrelevant.

**Mr J. Wilson:** I agree, but we tend to be a minority these days.

**Mr Wessinger:** Thank you very much for your presentation. It would be fair to say, though, that under the Consent to Treatment Act a parent has to give consent to treatment to a child. Would you not agree with that?

**Mr Nathwani:** Today, yes.

**Mr Wessinger:** You have one proposal you make, and I would like a little bit of elaboration on it. You say that, on page 4, "If a person who is over 16 can access an advocate if they are seen as vulnerable in a treatment situation, we feel a child should be able to access an advocate under the same situation." Do you believe a child of any age, or do you say—

**Mrs Troyer:** Yes, any age. There have been cases even in Canada where a child was born disabled and, because of the disability, the parents chose not to treat that child. That law was not upheld. Children's aid came in and seized that child. You have a choice as a parent to be a parent; that is your choice. But the child's rights should be the ultimate. It should not be the parent in the case of a disabled child.

**Mr Wessinger:** Are you saying that under the existing laws—this is of course not related to this act but is related to children's services. There are protective services available to children.

**Mrs Troyer:** No. I fiercely argue that, because when my son was born disabled, we were told to leave him in the hospital and allow him to die and go home. He was born in 1983. This is after the Grange commission. That is bullshit. That happens all the time; even kids that are Down's syndrome.

**The Chair:** Excuse me, you will have to temper your language.

**Mrs Troyer:** Sorry. My son is two and he has been denied treatment because of his disability and he is Down's syndrome. Down's syndrome is no big deal nowadays. There are 10 years of studies that would dispute a lot

of the things that people say; the mongoloid, vegetative state is no longer true. These kids are very productive in society and are very much a part of society and that, in many cases, is not taken into consideration.

When we took our son to the emergency with respiratory problems they said that Down's syndrome kids do this all the time and you can take him home. He was admitted 12 hours later in critical condition because he had tracheitis that had not been addressed and would have died if we had followed the doctor's recommendation. Those are normal things. That is standard procedure, that you keep a child for 24 hours after they have aspirated. We are not asking for special treatment for these kids. We are asking for the norm, and that is being denied, because when you take a child who is disabled into a hospital, they see the disability and that is the priority, that is the basis for their care, and that is wrong. I did not bring Alex to the emergency room because he was Down's syndrome; I brought him because he was not breathing. That should be the only thing that is looked at.

**Mr Winninger:** Just a couple of brief questions. I do not think anyone would disagree with you that guardianship should be the last resort. In many situations, the family, relatives or friends offer a benign influence that can actually empower the vulnerable person, and in some cases, the vulnerable person or the family may seek guardianship. But you would agree with me that does not necessarily diminish the empowering, the nurturing relationship that might exist between—

**Mrs Troyer:** I would question, if that was the scenario, why they would want the guardianship anyway.

**Mr Winninger:** That may be a good question.

**Mrs Troyer:** That is what I would question.

**Mr Winninger:** There may be circumstances where in order to maintain stability or consistency of treatment—I would ask you this, though. Would you not agree that there are situations where there are no nurturing friends, family or relatives, or where there are friends, family or relatives but they are exploiting, neglecting or abusing the vulnerable person?

**Mrs Troyer:** Yes. I agree that exists, but would you penalize a person because he is isolated and segregated?

**Mr Winninger:** If you want to regard guardianship as penalizing, I submit that guardianship in a situation like that may be a lesser evil than abuse or exploitation.

**Mrs Troyer:** It may be the lesser evil, but what I would suggest is that you look at offering the person support, establishing a circle of friends. Do all that other stuff before you look at guardianship. Just because someone is vulnerable and isolated, there are ways of counteracting that without enforcing a guardianship.

**Mr Winninger:** So you are saying explore the least restrictive alternatives.

**Mrs Troyer:** Yes.

**Mr Winninger:** One more question, if I may. You made the point, as other delegations have made, that advocacy should precede consent to treatment and substitute decisions. Do you not run the danger, in that scenario, that

advocates who visit with a vulnerable adult may be forced, if you will, into making decisions for the vulnerable adult that they really do not have the authority to make, simply because there is no framework for decision-making?

**Mr Nathwani:** We think that if you do not have substitute decision-making for the next couple of years, it is not going to harm Ontario. On a very fundamental plane again, taking the example you mentioned to Kathy Troyer a while ago, I am more interested in making sure the vulnerable adult has a good advocate, a good lawyer before he gets a good guardian. There is nobody to make a substitute decision, and decisions do not get made. I think that is the lesser of the two evils, until we sort it out.

**Mr Winninger:** I see.

**Mr Nathwani:** I am giving you a for instance now.

**Mr Winninger:** Thank you.

**Ms Carter:** Another aspect of the Advocacy Act is that it will have long-term implications in raising awareness as to how people we have dismissed as being disabled do have their points of view and their abilities and so on. How do you feel about this part of it; that it will, by raising societal awareness, make the kind of care you are thinking of more prevalent?

**Mrs Troyer:** That is all well and good, and doing that may help, but still, they need the right to that treatment. They need it by right, not just because someone chooses to allow them to have that treatment. It should be that they get it by right, period. That is not the norm in Ontario right now. And yes, they need to be educated and that education needs to happen, but still, they need to have that right that would ensure that if the other education falls through or is not followed up on, at least those people are protected by right.

**Ms Carter:** That is the bottom line.

1140

**Mr Nathwani:** May I just make a small comment on this? I will try to answer it in a bit of an oblique way. A lot of people, like the Advocacy Resource Centre for the Handicapped, will concentrate on a major charter case, and sometimes you have a major charter case that can affect the acts of individuals. I think the Advocacy Act is going to help us in the trenches, in the IPRCs, the various little tribunals in God knows how many different places where you cannot possibly have ARCH or lawyers like that interested in it. I think it will raise our sensitivity. Sure, there will be hitches; sure, there will be glitches. Things will not work out, and there may be occasional budgetary problems, but it will make it more pervasive and raise consciousness.

**The Chair:** Ms Troyer, Mr Nathwani, on behalf of the committee, I would like to thank you for taking the time out this morning and coming and giving us your presentation.

**Mr Nathwani:** Thank you for listening to us. You have been very patient.

#### ONTARIO COALITION OF SENIOR CITIZENS ORGANIZATIONS

**The Chair:** I would like to call forward our next presenters, from the Ontario Coalition of Senior Citizens

Organizations. Good morning. Could you please identify yourselves for the record and then proceed.

**Mr Triantis:** I am Stephen Triantis, professor emeritus of economics, University of Toronto, and I am representing here the Ontario Coalition of Senior Citizens Organizations. My colleague is Mary Allen-Armiento, also representing the Ontario Coalition of Senior Citizens Organizations.

We looked at the three bills—that is, the advocacy, substitute decision-making and consent to treatment—and we found the advocacy the least satisfactory. Indeed, we thought it quite deficient. It is bureaucratic, it has a lot of bones and skeletons, and all you have to do is look at the table of contents; there is not much flesh on advocacy. The act is about advocacy, and that is the flesh. You would think that Bill 74, as it stands, would be a companion to another bill, the main bill, which would be on advocacy.

I am going to be more specific. The act is peripheral. It talks about what the commission of the advocates may or may not do, but not, first, what is an advocate and what are advocacy services, as we define in section 2 what is a vulnerable person. Advocacy is a vague and loose concept, yet the advocate is given a lot of legal authority by this bill, with legal implications. Should we not know what the advocacy involves? Even the French term is unsatisfactory. It talks about “*intervenants*,” somebody who intervenes without being called. The advocacy has an implication of some mandate being given to speak for that person or to act for that person, so we are still left with ignorance as to what is an advocate and what is advocacy.

Second, who can be an advocate and what qualifications must he have? Sure, there is a paragraph in section 36 that says the commission may make regulations establishing minimum qualifications and educational standards, but what about questions about the relationship of the advocate to the vulnerable person and to the facility in which he is, and conflicts of interest? It is not comforting at all to leave all that to the commission and not to you; that is, our legislative representatives.

Third, and above all, what is the advocate supposed to do in order to serve the purposes of the act? All we are told is the conditions on which he can enter and obtain information. In section 36 we are told that the commission may make regulations to establish procedures and standards governing the provision of the advocacy services but not what these services are. What can an advocate request from a facility? What means does he have to enforce anything he is requesting, or does the commission have?

Even the goals of advocacy mentioned in section 1 are peculiarly written: “1. The purposes of this act are,” and then (a), (b), (c), (d). Clause (a) may be “To contribute to the empowerment of vulnerable persons” etc, but clause (d) says, “To take into account the religion, culture and traditions of vulnerable persons.” That is a condition, a parameter; that is not a goal, so it should not be there.

Fourth, the advocate is appointed by the commission or by community programs for, what, a period, ad hoc in each case? If for a period, how is he assigned to this or that case? By whom? What is the relation of the advocate to the commission? Is it a master-servant relation? This is not shown in the act, and it should be.

Fifth, what are the responsibilities and the limits and liabilities of the advocate? Here we have somebody who is given a lot of power—and especially a lot of power and very important duties in the other two bills, 108 and 109—but we want to know what are his responsibilities as an advocate and what are the responsibilities of the commission that is sending him to this particular (a) or (b) case. What is the guarantee that the advocate is acting in the best interests of the vulnerable person?

If I may leave the advocate for a minute and turn to the vulnerable person, it is our feeling that an elderly person may be intimidated or afraid to act and to show that he needs an advocate. We know a lot about elder abuse in this province, or anywhere else. We feel that section 2 should be changed to read, “because of any infirmity or sickness” and so on “or other reason,” or “because of other reasons has difficulty in expressing,” because intimidation is tantamount to infirmity, which is what section 2 has in it.

In clause 7(b), reference is made to acting on the wishes of the vulnerable person. How about the best interests, and how about the wishes and the best interests brought into some compromise?

In subsections 19(2) and 21(2), provision is made for the advocate to meet the vulnerable person in a separate room, if possible. We do not like the “if possible.” It should always be in a separate room. I do not see why it should not be.

In subsection 21(3), “The advocate must leave the premises promptly if the vulnerable person indicates that he or she does not want the services of an advocate.” What if the vulnerable person is intimidated by the staff of the facility in which he is lodged? What if the vulnerable person does not understand the role and the purpose of the advocate? He may think he is a tax collector. What if the vulnerable person does not like this particular advocate but would deal quite gladly with another one? There are important things that we believe should be addressed.

Section 6, we think, should be rephrased. It says, “A majority of the members of the commission shall be persons who have or have had a mental or physical disability, illness or infirmity.” So anybody who has, right now, a mental disability is eligible to be a member of the commission. That obviously is not intended to be so, and that is why we believe it should be rephrased.

We found, on the whole, this bill extremely bureaucratic and formalistic and, as I said at the beginning, we just believe this should be a third of a total bill on advocacy or an adjunct to a bill on advocacy. So much for Bill 74.

1150

If I may, I would like to say a few words about Bill 108. It is just these two bills that I will address. We have not got many comments on the Consent to Treatment Act, although if you have any questions we would be glad to respond.

In Bill 108 the advocate is assigned all kinds of duties in sections 16, 20, 27, 49, 59 and 74. Frankly, you would have to conclude that he or she would have to be a philosopher, a psychologist, a lawyer, an economist, a social worker and everything else all combined. He would have to be a Solomon, a Freud, a Keynes, a Mother Teresa and

everything else all combined. I would like to see where we are going to get that kind of person.

**Mr Poirier:** Like an MPP, you mean.

**Mr Triantis:** Not quite, because he is a step above an MPP.

In section 45, the attorney or guardian, the personal guardian, has to be at least 16. We have found that this is a going a little bit too low. The person should be at least 18. It is odd that in order to serve as attorney or guardian of property you have to be 18, but that on this more important and difficult problem of dealing with a human being 16 is enough.

Reference is made in a number of sections, and I do not need to give you the sections, there are three or four, to a management plan. I just wonder whether this management plan should somehow be defined and described and delimited. The words may imply something formal, something professional, something grandiose. They make it difficult for a spouse or another relative to qualify as a guardian under this management plan.

In subsection 32(1) reference is made to the fact that the person must deal with “honesty and integrity.” I just wonder what the difference is. Mind you, I have seen that in many pieces of legislation and I still wonder what the difference is. I do not know whether another person wrote subsection 33(2), the second part of the section. Here we have only honesty. Honesty is mentioned, and that is enough. In section 63 integrity is not mentioned for some reason or other.

As far as section 63 is concerned, if I may refer you to the text, it is my view, and I put it there for your consideration, that in subsection 63(3), paragraphs 5 and 6 should be reversed: “The guardian shall take the person’s current wishes into consideration, if they can be ascertained”; and then comes what is now number 5: “If no instructions or wishes can be ascertained, the guardian shall make decisions on the person’s behalf that are likely to promote the person’s wellbeing.” It seems to me as if these two are in the wrong place, upside-down.

In section 24 provision is made that the person appointed as guardian must be a resident of this province. I respectfully submit that you should add, “shall not as a rule be appointed.” But there could be exceptions. There could be somebody who lives next door or in the next province who is an expert, or there could be somebody living in Hull and taking care of an incapable person who lives in Ottawa, so “as a rule” would be better.

Another question we have is, should there not be somewhere some provision as to what persons are excluded from being attorneys or statutory guardians or court-appointed guardians of property on account of criminal record, on account of lack of qualifications? Should there not also be a second provision how they are removed if and when such things occur, or if and when such record is discovered? I have the same remarks about the attorneys and guardians for personal care, some provision as to what persons disqualify.

In section 43 and elsewhere there is provision for passing the accounts. I presume that “passing the accounts” is a legal

or a chartered accountant term, "passing" meaning approved by the courts, I presume. I just wonder whether some explanation of the words "to pass the account" should be included in the definitions in section 1 to avoid any ambiguity. You pass an exam and so on. It is ambiguous.

Finally, in section 56 it says: "Unless the order expressly provides otherwise, the guardian does not have power" to change so and so "or to give consent on the person's behalf to the adoption of a child." Maybe that is rare or maybe it is not so rare. If the person did not have the sagacity to expressly provide for the guardian being able to consent to the adoption of a child by this person, then that might, may I say, create problems.

While we have expressed some of our concerns as seniors and we are grateful for the opportunity to do so, seniors in this province have been battered and often treated casually and harshly. I say that for everybody. This is our feeling. Seniors have been grossly victimized. Their living depends on a fixed income. We have been emphatically and loudly promised pension indexing and in a year and a half of this government we have seen nothing.

This is not a measure requiring government finances so you would say that the government cannot afford that. It simply involves using some of the large surpluses in the pension funds to provide for the pensioner so he does not go down the drain every year. We are here to emphasize, and I hope we have other opportunities, some of the many problems which are hurting the seniors, or one sixth of the voters of this province. Thank you very much.

**Mr Chiarelli:** Thank you very much, professor. I think you have made some very good points, particularly with respect to the advocacy provisions. I cannot help but think that before this legislation was finalized you probably could have been a devil's advocate for legislative counsel.

I think that in many ways you raise the same points that Professor Lowy from the University of Toronto raised. He raised some very serious concerns about the advocacy legislation. He said it is good in principle. He said he compliments the government for considering bringing advocacy legislation forward, but that there should be a pilot project for starters, because there are so many questions, it is a new model, we are going into new territory and because it affects people so personally, technically, legally etc, that it would be appropriate to proceed with the advocacy legislation on a pilot project, in effect, an experimental project.

Certainly all the concerns you are raising today, loopholes, the items that are not covered, the inconsistencies etc, would emphasize to me that this legislation is not ready to go forward. Your colleague, Professor Lowy of the University of Toronto, who is very experienced in many of these areas, has said we should proceed with a pilot project. Do you see that as a viable alternative, or alternatively, do you think we should simply go back to the drawing boards and put the other two thirds of the legislation together before we proceed?

1200

**Mr Triantis:** That is Dr Lowy, the ex-dean of medicine. I respect his view. His view and my view coincide in

the sense that we both have trouble with the bill as it is. Whether you can pass a bill and apply it on a pilot basis I do not know. It is really for you legislators to know whether this can be done. Frankly, I would have it back to the drawing board and go through with it, in view of what I said today and what I guess other people have to say, including Dr Lowy.

**Mr Chiarelli:** My only comment is that I do not know whether you have the benefit of seeing other briefs or reading Hansard. My understanding is that most of the technically qualified people, most of the people who are working in the field, have serious concerns about the adequacy of the legislation at this particular point in time. I would certainly hope that the government would look at its agenda and go back to the drawing board and try to create some kind of consensus among the people who are interested in this legislation.

I see that you represent a coalition of seniors' groups. Could you perhaps describe very briefly the nature of that coalition and how many people you are properly representing here today?

**Mrs Allen-Armiento:** We represent three of the Indian bands as well, but we have about 35 groups of seniors, including the teachers. I myself represent the primary care givers in the Italian-speaking group. I have about 250 families. My interest in this is that after spending so much time on it at first I welcomed it. It was certainly due, from the reports I get and the fear of some of the seniors, especially those with Alzheimer's, to have to go into the hospital, or even the fear that some day they may have to go and what is going to happen to them. There is a great deal of fear.

There are a lot of cases which we could not help because you cannot enter a hospital at a certain time, there are just visitors' times to really pin them down. I tried to explain this act. At first they said, "Thank God we have this." I have read it. We have studied so long. I still have not been able to explain it to them. I can just tell you one comment of one of the seniors, who said, "I think we're still back in God's hands." He could not see any benefit of this because it was too complicated and where do we go, especially with the linguistic problem?

**Mr Triantis:** To your question, I reply that the coalition represents about 35 organizations, some with thousands of members and some with fewer. I have not got a detailed list, but it is a very large number that we represent and we did consult with them also.

**Mr Chiarelli:** Along with your concerns about the definition of what advocacy or advocacy services are, I wonder if I could ask legislative counsel a question. One of the items you did not raise that I have a question on is in section 1 where it says:

"The purposes of this act are to provide advocacy services to help vulnerable persons," and then in subclause (ii), "bring about structural changes at the political, legal, social, economic and institutional levels."

What does the term "political" mean? Is that intended to be synonymous with "governmental" or is it intended to suggest that advocacy would take place as far down the line as political parties and political campaigns and political

matters? Should that not be "governmental level" or in fact does it mean "political"? I am asking that to legislative counsel.

**Ms Spinks:** I should properly ask legislative counsel to the Ministry of Citizenship perhaps, but I understand the term is really designed to refer to changes in the laws that may be necessary and so forth, not to emphasize political lobbying or things of that nature.

**Mr Chiarelli:** But what does the section say? To me, the section says that advocates who are coming from a government commission paid for through a government agency are being asked to advocate in the political context. "Political" is a very specific word. It does not say "governmental change," it does not say "change of government policy," it uses the term "political." I would have very serious concerns about the Advocacy Commission getting involved in what is defined as political change and the political level. If you are talking about governmental and interfacing with governments, that is one thing, but if you are talking about political, which is what the section says, that is quite another. I certainly would add that to the list of concerns that were raised here about very imprecise definitions and framework for the whole question of advocates' responsibilities.

**Mr Triantis:** May I add to that, since we are on the purposes of the act. Under clause 1(c) it says, "To ensure that community development strategies are applied in the provision of advocacy services." For three decades I have taught economic development and planning, and frankly, what this community development strategy is should be spelled out in some way.

**Mr J. Wilson:** Just to carry on with what Mr Chiarelli was getting at, I suggested last week that because the word "political" is there, if it is not struck, we should ensure that advocates and members of the commission by law not be able to get involved in partisan political campaigns and political parties. I figure that is the only way to safeguard that this does not become some lobbying group for one particular political party.

In the composition of the commission, you did mention perhaps the wording of having people who are either psychiatric survivors or mentally ill at the time serving on the commission. The wording there does seem a little dubious, but I think you will hear from the government that it fully intends the majority of the commissioners to be people who are either survivors or currently in treatment; vulnerable persons anyway. Just looking at the makeup, the majority of the commission would be made up of vulnerable people.

This is the first time in Ontario's history we have established an arm's-length commission that is not only told it is supposed to be political but it is already biased because it is made up in the majority of people it is intended to serve. Does that bother you from a citizens' group point of view? How are you going to get impartial, balanced decisions when it already has a bias? As one group already explained to us, it is already partisan.

**Mr Triantis:** My point was that here it says people "who have or have had a mental or physical disability...or infirmity." So you can have people on the commission

who are mentally disabled according to the way it is phrased.

**Mr J. Wilson:** That aside, though, do you have any concerns with the weighting of that commission? It is a precedent. Normally when government sets up an arm's-length commission, it tries to put in a balance of perceived interests. This is definitely tilted in favour of the interest group it is serving and there is a conflict-of-interest question.

**Mr Triantis:** I would be inclined to agree with you. I am not a doctor and I do not know how many people who are mentally disabled become well again, so what do you have, unless you have a majority of physically disabled people. And there the question is, how much do the physically disabled people require an advocate? I do share your concern.

**Ms Carter:** I just want to raise two points. One is, you raise the question of wishes versus best interests of a person, and I think that is a very crucial point. I could say to you, if you became incapacitated and you had somebody to interpret what you want, would you really want him to be acting in what he thought as your best interests or on your wishes? I think children very commonly get treated and instructed for their best interests, but surely when we become adults we have the right to drink and smoke and do things because we like to do them, even though they may not be terribly good for us. I am just wondering if that is really what you meant.

1210

**Mr Triantis:** I frankly believe it should be the best interests, because the wishes I express—if somebody takes my wishes today, next month I am travelling to Australia on a lecture tour and I feel okay. If I am incapacitated and they say, "This person really liked to travel," no, the best interests would be different from my wishes, because they do not know my wishes when I am incapacitated and therefore my best interests should really be the important point.

**Ms Carter:** Obviously if you are incapacitated you are probably not going off on a long journey because you want to, but I think there are much smaller things in life where you have your preferences and your choices. I think the object of an advocate is to listen to the person, rather than to turn around and say, "This is what you ought to be wanting." I think that is a decision that should be clear.

If you are incapacitated, of course you also need somebody to protect your rights and your point of view against people who maybe claim to be speaking for you but actually are not, for example, if relatives were trying to get hold of your estate and saying, "Oh, well, he is incapacitated; he can't do that," and you do not feel you are that incompetent. You need somebody to defend you, and that would be the advocate's role.

**Mr Triantis:** I see your point, which is very rational. My question is, how do you ascertain the wishes? You only know the wishes of yesterday; you do not know the wishes of today or what would be the wishes today. Therefore, somewhere along the way there should be some balance struck between wishes and best interests.

**Ms Carter:** I think a lot of the vulnerable people were thinking of people not so far incapacitated that they cannot

still express wishes. Certainly you represent the senior citizens and I think that would be the case with a lot of older people, that they still know what they want but they do not have the ability to make those wishes stick, as it were, so they need an advocate.

My other point is, what qualifications do you think an advocate should have?

**Mr Triantis:** God almighty, the task is being given in the other two bills. As I said before, he should be Solomon himself. I would not take on that job. Not that I am so wise, but all I am saying is that I would find it overly difficult. I have a legal background and an economics background, but there is a lot more I would have to have.

**Mrs Allen-Armiento:** Especially as they would have to be culturally sensitive to the different culture of that person. That adds more, which is the makeup of our society.

**Mr Triantis:** That is something to be worked out.

**Mr Winninger:** Thank you, Professor Triantis. I do not know if you were saying this entirely tongue in cheek, that the advocate had to fulfil the role of Solomon here, be the person for all seasons, the psychologist, psychiatrist, theologian, what have you. Is it not important that the advocate know where the resources are to be able to direct the vulnerable adult in the right direction, be it to a psychiatrist, doctor, theologian or whatever? They do not have to embody those qualities themselves necessarily, but they have to know where to find the assistance and they assist in finding assistance. I just wondered if you were aware that the role of the advocate is more modest perhaps than you envisage.

**Mr Triantis:** Then we should give them a 100 course in psychiatry, psychology, theology, as you said, and so on, and then they will know how to deal with these other specialties.

**Mr Winninger:** Just one supplementary question dealing with Bill 108: Do you see a need for powers of attorney for personal care and in some cases guardianship orders?

**Mr Triantis:** Do I see a need?

**Mr Winninger:** Do you see a basic need for that?

**Mr Triantis:** Oh, yes. Yes, I do.

**Mr Malkowski:** Just briefly, do you have any specific recommendations or suggestions in terms of qualifications of the advocates related to their role and responsibilities?

**Mr Triantis:** The question is related to the question I was asked by Mr Winninger. I do not have an answer offhand. All I can say is that in society you will find that preference will be given to lawyers and accountants. Whether the lawyer or the accountant is the right person to be an advocate, rather than the social worker or the psychologist, I do not know. This is something I cannot give an answer to at this point. If I were part of a committee thinking out this problem, maybe I should and I could.

**Mr Malkowski:** Then you would support the Advocacy Act in terms of helping seniors and to protect seniors from abusive situations?

**Mr Triantis:** I support an advocacy act and I support the notion of advocacy, just as I support the notion of motherhood, but there is a long distance between an advocacy act which is properly done, which is complete, which does not have the defects or the incompleteness we see, an advocacy act of that kind, and the Advocacy Act we have in front of us, Bill 74. I do support an advocacy act, I do support the notion of an advocacy, yes, but not the way this bill is structured.

**The Chair:** On behalf of the committee I would like to thank you for taking the time out this morning and coming to give your presentation.

I would like to announce there will be a subcommittee meeting at 1:25 this afternoon. This committee stands recessed until 1:30.

The committee recessed at 1217.

## AFTERNOON SITTING

The committee resumed at 1334.

## SUBCOMMITTEE REPORT

**The Vice-Chair:** First off, I would like to let you know that the subcommittee met at 1:25. I have a report: "Assuming that the House is not sitting, the subcommittee recommends that the Chair ask the House leaders and whips to allow this committee to sit for the purpose of further public hearings during the week of March 23." Any discussion? All those in favour?

**Mr Fletcher:** Can we have 10 minutes?

**The Vice-Chair:** Are you asking for a 10-minute recess? We are recessed for 10 minutes.

The committee recessed at 1335.

1345

**The Vice-Chair:** All those in favour of the subcommittee report, please show. All those opposed? The subcommittee report is defeated.

The first presenter I would like to call this afternoon is the Advocacy Resource Centre for the Handicapped.

**Mr J. Wilson:** Mr Chair, what is the sense of having a subcommittee meeting when the three parties agreed on something and now they do not agree?

**The Vice-Chair:** Each member, Mr Wilson, has the right to vote as he wants when in committee.

**Mr J. Wilson:** Well, you guys should know what you are doing before we have a subcommittee meeting.

**Mr Chiarelli:** I have a motion.

**The Vice-Chair:** Mr Chiarelli moves that the committee not report this legislation to the Legislature until January 1, 1993, or later.

**Mr Chiarelli:** I would like to comment. I may be commenting on this at some length, so I am going to give you some fair warning on that particular point.

**The Vice-Chair:** Can I ask that the witness be excused then, so that she does not have to sit right there?

**Mr Chiarelli:** That is fine.

**The Vice-Chair:** Okay, you can be excused for a few moments. Mr Chiarelli, would you mind delaying the discussion until the end of the last presenter this afternoon?

**Mr Chiarelli:** I do mind; I would prefer to go ahead with my motion.

**The Vice-Chair:** By all means.

**Mr Chiarelli:** Thank you. I am concerned about the progress of this legislation. I am concerned about how responsibly or otherwise the government members are conducting themselves with respect to these hearings. As I mentioned on another motion last week, I believe this legislation is the type towards which which any government must work to develop a very broad consensus. We are talking about legislation that impacts very directly and personally on almost every citizen of this province.

Each one of our fellow citizens will be dealing with this legislation, through older parents, through vulnerable

people in their family or close to them. We are talking about legal documents, we are talking about legal advice that will be given to mature adults in every legal office in the province of Ontario. Yet we have seen here, since these hearings have commenced, a very broad consensus that we ought not to be dealing with this legislation in its current form, or at least not within the present legislative straitjacket.

We have live legislation. We have a bill that has gone through first and second reading. As I understand it, we are going to be looking at clause-by-clause and amendments to this legislation. My assessment, my looking at the situation through the words of the presenters who have come here has indicated that this legislation needs to be redesigned. There is a consensus, in principle, that the Mental Health Act advocacy legislation has to be relegislated and modernized in a very significant way, but there also is the consensus that the present legislation is not workable. Each individual bill has serious flaws in it and the workings between these bills have serious flaws in them.

That being the case, I had real trouble understanding when last week, when we had come before us a witness such as Dan Ferguson, who is very experienced in this whole area, we did not have agreement from the government side to permit an extra 10 minutes of questioning because he had used his full time. Yet today we can go to 12:20 or 12:15, when last week I asked only that we go to 12:10 or 12:08, in order to ask that very important witness some questions.

Today we had a subcommittee meeting in which we had a very simple discussion; that is, we had a number of people who had requested to come before this committee and make presentations and we had an all-party agreement at exactly 1:25 to present to this committee that we have an extra week's sitting, an extra week which became available because the government has indicated that it intends to convene the Legislature later. The subcommittee report was presented and a request was made to adjourn for 10 minutes, so the government side could go out and discuss the issue.

Mr Chairman, to be very frank, I wanted to use that opportunity to go out and make a phone call to my office to see what was going on in terms of messages. As I was walking out to the phone, I overheard the government caucus talking about CBC programs, CBC interviews etc, and the main concern obviously was the fact that the media were dealing with this legislation in some fashion, which I find absolutely, totally offensive.

**The Vice-Chair:** Is that a point of order, Mr Fletcher?

**Mr Fletcher:** Yes, Mr Chair. What was heard was out of context of the whole conversation, and Mr Chiarelli is using it to make it sound as if there was some devious plot going on.

**The Vice-Chair:** That is not a point of order, Mr Fletcher. Mr Chiarelli, please.

**Mr Chiarelli:** I am not suggesting there is any devious plot whatsoever. I think what the government is doing is

quite clear. It intends to proceed with this specific legislation when there is a consensus among most of the people who have come forward so far that they do not want this legislation to go ahead in its present form. I repeat, the substance of my motion is that I do not think the people of Ontario and I do not think a lot of the special interest groups and the citizens who are coming here as individuals are ready for this legislation to be implemented. On the other hand, I see the government as being on a course where it intends to complete the three weeks of hearings, move to clause-by-clause and bring this legislation in for third reading, if and when the Legislature is ever reconvened.

I believe this is not the will and intention of the majority of people who want to deal with this legislation. I think the majority of people who want to deal with this legislation want to try to come up with a consensus. They realize that we are dealing with very substantive legislation that is going to impact on every single person in this province. Rushing it through in the manner the government and this committee are rushing it through is irresponsible and not in keeping with the submissions that have been presented to this committee to date.

I can only repeat what somebody like Dr Lowy indicated to the committee last week that, in principle, this legislation is good; however, we should be redesigning it so that it is a pilot project. He said that we are talking about health care issues in a very highly technical and legal area. We are also talking about treatment of vulnerable individuals and how they are going to be treated. We are talking as much about a medical problem as we are about a legal and social problem. Dr Lowy, from his perspective at the University of Toronto—I believe former head of the faculty—has indicated that one simply does not proceed with widespread medical treatment and medical procedures without significant trial-and-error experimentation in a very scientific, cautious and conservative manner. He expressed concern that we in fact are passing legislation which is a new model without any experience in the field.

I believe strongly that the legislation needs to be worked and massaged and that individual amendments at the clause-by-clause stage will be totally, absolutely inappropriate for this type of legislation. We are going to end up with a network of confusion on the part of lawyers, social workers, medical practitioners and families of vulnerable people in this province.

It is a matter that will require a total communication package throughout the province in as concentrated and as widespread a fashion as possible from the point of view of the legal profession having to create seminars and having to put together a very massive program of educating the profession. The legal profession will have to be educated in a very major way. Medical practitioners of every type will have to be educated in a very major way. People working in the field, advocates, will have to be educated in a very major way.

Yet we are rushing this legislation through. We have had the most pre-eminent experts who are available in the province of Ontario to date come before this committee and

say it is premature to deal with the legislation in the way we are dealing with it now. I find it is highly irresponsible.

I believe if this legislation and this matter were not to be reported to the House until some time after January 1, 1993, cooler heads would prevail. The opportunity would exist for these special interest groups, these professions, to talk to people in the government to try to persuade them. I really believe that the government members of this committee are having trouble assessing the impact and the importance of this legislation and that they are hell-bent for third reading and getting it through as quickly as possible.

I would prefer to see this matter dealt with in as non-partisan a way as possible. We are not talking about Sunday shopping. We are not talking about rent control. We are talking about the very substance of the lives of thousands and thousands of people of this province, vulnerable people, senior citizens. I cannot conceive of a government that would want to proceed without a broad consensus on the particulars of the legislation.

There was an indication last week that they would not permit 10 minutes to ask questions of an individual. There was agreement at 1:25 today that we are going to open it up for another week of hearings so people who have requested to come in to make submissions can come in. We have an ad hoc meeting out in the hall where the government side goes out and says: "We've changed our mind. We're not going to have any more hearings on this issue."

How appalling, how unbelievable for a government that is supposed to be open, that wants to listen and that wants to consult—and sits there and smiles because I am saying what I am saying. Get serious. Do what you say you are going to do. If you are going to consult, and you want to redo how we do business in the province and how people conduct their lives in a serious way, then open the doors and open your mind and do things the right way.

**Mr Fletcher:** You've already wasted people's time.

**Mr Chiarelli:** I have not wasted any time, Mr Fletcher.

**Mr Fletcher:** What did you do? Five years. Tell us what you did.

**Mr Chiarelli:** That is right, and I have to apologize to the people who are here, because the people who are coming in from day to day, a lot of them, do not understand the context of what a lot of the submissions are in this process, what people are saying from day to day in their briefs and who is saying it.

A lot of people have said basically, and I agree with it, that the problems under the Mental Health Act and the problems with advocacy in this province have to be addressed. There are serious problems. But we are not doing it the right way. We are not doing it in an open way. We are restricting the debate. We are restricting the consultation. I believe I have said what you want to do—

**Mr Morrow:** On a point of order, Mr Chair: I do believe that we are hearing more deponents than any other committee this session.

**The Chair:** You do not have a point of order, Mr Morrow.

**Mr Chiarelli:** I understand that you have three weeks of hearings, that you are hearing a lot of deputants. But I also think it is imperative and the principle under which I am making my motion is to respond to what those many deputants have said to date, and to respond to the fact that today you said even though you have time in subcommittee you are not going to open it up for additional hearings to people who are calling, including the Advocates' Society, Duncan P. Read, executive director, who wants to come in and make a submission. We are saying to the Advocates' Society, "No, we are not providing additional time for you to come in." We are saying to other groups, "No, we are not providing time for you to come in."

1400

We are not talking about an imperative piece of legislation that must be legislated by June 1 or June 30. We are talking about legislation that will be very difficult to amend after the fact. We are talking about legislation that will impact upon almost every profession—other than the accounting and engineering professions—all the health professions and the legal profession in a very, very significant way.

I am going to conclude my remarks very quickly, because I am concerned that we have people who are waiting to make submissions. I just want to say that the attitude of the members of this committee, I hope, does not reflect the attitude of the Premier. I think if the Premier were sitting here seeing the deliberations of this committee and how they are dealing with the issues and how they are closing the door to suggestions that are made honestly and openly by opposition members and members of the public, he would be very disappointed in his members of this committee who are elected to serve the people of Ontario. I will conclude my remarks with that.

**The Chair:** Thank you, Mr Chiarelli. Further debate on the motion, Mr Wilson.

**Mr J. Wilson:** Perhaps the parliamentary assistant could answer this. Stemming from the motion, I would like to know why the government changed its mind so abruptly and will not allow an extra one week of committee hearings for the one dozen groups, I think, that have asked to appear before this committee. What would the reasoning be for that? If you have not changed your mind, which Mr Fletcher and Mr Morrow who sat in the meeting are trying to tell me is untrue, then what would the reasoning be for not allowing an extra week of committee hearings when so many people want an opportunity to speak to this committee?

**Mr Malkowski:** I would like to respond very directly to Mr Chiarelli and to Mr Wilson's comments. Up till now, historically, people have brought up the issue of advocacy. The Tory government introduced the psychiatric patient advocate office and that system was established. The Liberal government set up the O'Sullivan report that looked at advocacy. There was the Fram report that made strong recommendations in terms of setting up an advocacy commission. So we do have those recommendations. We have heard the three parties agreeing on the concept of advocacy in the House. That is already on record. We have already heard from different groups and presenters, adult

protective service workers, their concerned friends, psychiatric survivors, the different groups that made presentations. They were all very clear that they are in support of advocacy.

Mr Chiarelli, I would like to make a point very directly with you. You have missed several of those presentations, Thursday afternoon and Friday.

**The Chair:** Through the Chair, please.

**Mr Malkowski:** Sorry, Mr Chair. Several presentations have been missed.

**The Chair:** That is out of order, Mr Malkowski.

**Mr Chiarelli:** I do not mind if he talks directly to me.

**Mr Malkowski:** You are right. We do not want to waste time, and we do not want to waste the people's time who have come here. I think it is time to do something in terms of setting up the Advocacy Commission. We have been already working on this for 20 years so, come on, we need to go ahead with it. I think we need to respond by setting up the Advocacy Commission, to go ahead and do that.

Now I would like to focus on the presenters because they are ready and I do not want to waste their time. I think we need to move on.

**Mr J. Wilson:** I did not really get an answer to my question, because we are not talking about delaying; although the motion, and I have not said whether I am in favour of it or not, talks about delaying introduction of the committee's report. My question was, why can we not have an extra week, given that we know the House is not coming back on March 23? It will be coming back mid-April is my guess. We certainly have the time. It would not delay introduction and we have people who have concerns they want to bring forward.

**The Chair:** The committee has voted against extending for one extra week.

**Mr J. Wilson:** I think the people of Ontario are entitled to know the reason.

**The Chair:** The committee has decided not to; that is all I can say.

Motion negatived.

#### ADVOCACY RESOURCE CENTRE FOR THE HANDICAPPED

**The Chair:** I would like to call forward our next presenter, from the Advocacy Resource Centre for the Handicapped. Good afternoon. Would you please identify yourself for the record and then proceed.

**Ms McKague:** My name is Carla McKague. I am the senior litigation lawyer for the Advocacy Resource Centre for the Handicapped, which some of you will know as ARCH. In view of the preceding motion, I want to begin a little differently than I had intended to begin today.

I want to begin by pointing out two facts. The first is that debate, discussion, consultation and committee meetings on the issues addressed in this legislation have already gone on in this province for over 12 years, and 12 years is enough.

The second thing I want to point out: Mr Chiarelli has been addressing the issue of what the majority of people in Ontario want. I want to give you some idea of the size of

the constituency I am here to speak on behalf of: 20% of people in Ontario have been or will be inmates of a psychiatric institution, one in five Ontarians; 3% of Ontarians have developed mental disabilities. We are already up to almost a quarter of this province and I have not even yet got to physical disabilities or to the elderly. We are talking about a sizeable number of people. We are talking about close to one half of this province that will be directly affected by this legislation, affected not because they are providing services under it, but because they are receiving services under it. That is a voice, I would submit to you, that deserves to be listened to.

Let me go back to where I intended to start. Some of you know who we are. Some of you are familiar with ARCH; some of you are not. What we are is a community legal clinic. We are funded primarily by the Ontario legal aid plan. Our concerns are with people who have disabilities, physical or mental. We are governed by a board composed of representatives of 40 member organizations. The majority of our board are themselves people with disabilities. We very rarely speak with an independent voice. We take generally the traditional role of lawyers, which is to represent our clients and to speak on behalf of our clients.

There is, however, one area in which our board has said we have our own voice, and that is the area of advocacy. We have been instructed by our board for a long time to speak out as strongly as we can and as powerfully as we can for the introduction of a system of lay advocacy. We are therefore here primarily to speak to Bill 74. We will be addressing some comments to Bills 108, 109 and 110. We are not going to address Bills 7 and 8 before you because we feel that the concerns they deal with, which are very real concerns, are adequately dealt with by the other legislation.

We have had 12 years, since our founding in 1980, of experience with the very, very serious and pressing concerns of our community. One of the things that has been apparent to us throughout those 12 years is the desperate need for our clients to have people who are not necessarily lawyers assist them in making their problems and concerns known.

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It is not a matter of identifying the problems. I can assure you we know what the problems are. The central ones—I have given you a written copy of this, so I will summarize—are unemployment, poverty, vulnerability to abuse, lack of physical access, lack of access to information, lack of access to adequate services, and daily encounters with discrimination, stereotyping and appalling treatment by other people.

Some of these problems have legal solutions and some do not. Many need the help of a lay advocate, someone who can come into the picture, not to define the problem—we have done that—but to assist the person in being heard. The reality is that people with a disability are often unable to make their unassisted voices heard. They may have difficulty speaking or hearing. They may be in a situation of total dependence on an oppressor or an exploiter. They may simply lack credibility: No one is going to listen to them, because they are crazy or they are dumb.

Ideally, this would be a society in which anyone could speak out and be heard and be respected, but that is not so.

The fact is that if you are looking, for instance, at the situation of a young woman with a developmental disability who is routinely and repeatedly sexually assaulted by a family member, she cannot solve that problem on her own. The person with a physical handicap such as cerebral palsy, who is taunted by others and abused, does not know where to go for help. The elderly woman in the nursing home who has inedible food and inadequate personal care needs assistance. The problem is very clear.

We want to speak in the strongest possible terms about the need for this proposed advocacy system. Many people in this province—as I have suggested, perhaps close to half the people in this province—at one time or another need skilled, caring allies who can not only assist them but can also help them learn how to make their voice heard unassisted.

We do have some concerns with details in Bill 74, but I emphasize very strongly that these are details and only details. We are talking about minor cosmetic surgery and not about radical restructuring, and we urge this committee in the Legislature to pass and proclaim this legislation with all possible speed. I am not even going to address the details for the most part.

You will be hearing later this week from the Ontario Advocacy Coalition, a group of which we are a member, and we support and adopt virtually all of its recommendations. There is one that I have mentioned in the written material you have about which we do not take a position for or against. That is their recommendation that there be an amendment to the act to allow an advocate to break confidentiality in order to report the risk of a vulnerable person's doing harm to himself or herself. This is a very controversial area within our community and we simply take no position.

As far as Bills 108, 109 and 110 are concerned, again, at this point I am not speaking with ARCH'S voice. I am speaking here reflecting a consensus among our member groups and our constituents. We are, however, at first hand very painfully aware of the problems that exist in Ontario because of gaps in our law around decision-making for people judged incompetent to make decisions personally. We get calls virtually daily arising from these gaps.

What we have here, and I want to make this very clear to you, is a situation in which, with the sole exception of treatment in psychiatric facilities, virtually every decision made in respect of an incompetent person is legally invalid. Virtually all health care provided to incompetent people is illegal and legally constitutes an assault. There is no legal protection for the subject of the decisions or for the decision-makers. We go through enormous frustrations dealing with this total hiatus, this total chasm in the legislation.

As one example, we regularly see intrusive, unpleasant behaviour modification applied to developmentally disabled adults, either in provincial facilities or in group homes, and we know it is illegal. We know that you cannot legally do that to people. But if we go in and say it is illegal, our foundation for saying that is that, "Everything you are doing for and to these people is illegal." We cannot bring down the bad without bringing down the good along with it and taking away the foundation for this whole sys-

tem of supports and services to people with developmental disabilities.

The scheme that is proposed in this legislation would resolve that problem. Again, we have problems with some of the details, which I will address briefly, but the principles are sound—provided, always, that we remember the need for an advocacy system to go with it so we do not repeat the experience elsewhere of sweeping too many people under state paternalism.

Again, we are for the most part going to adopt the recommendations you will be hearing on Thursday from the Ontario Advocacy Coalition. However, there are two or three that I do want to specifically address.

The first is one on which we are not adopting the coalition's submission, nor are we saying you should not adopt it. It is one on which our community is so divided that there is not a consensus from which we can speak. That is the issue of whether partial guardianship ought to be included in the bill. There are members of our community who feel very strongly on both sides and, consequently, we feel that we should take no position on that submission.

On the other things I am going to mention, we support the coalition and we consider these of particular importance.

We know, and I believe Mr Chiarelli mentioned this earlier, that some groups have expressed concern to you that Bill 109 is modelled on the consent provisions of the current Mental Health Act. You have been told that the current Mental Health Act does not work and that it makes it hard to provide treatment to people in need of it. We must differ with those submissions to you. The problems that have been reported to you are not problems of the Mental Health Act. They are problems that arise from a profound and wilful misunderstanding of that act both by family organizations and mental health care professionals.

I have a friend who chairs one of this province's review board panels who talks quite often about the fact that this province has two mental health acts. There is the real one and there is the one that is discussed in the Toronto Sun. It is the one that is discussed in the Toronto Sun that causes the problems. It is the one that is discussed in the Toronto Sun that says you cannot commit people unless they are going to kill themselves in the next five minutes and that you cannot treat incompetent people. That is not what the actual legislation says. The actual legislation makes it perfectly possible to provide hospitalization and treatment to people who are at risk. You need to know that and not listen to the Toronto Sun version of the Mental Health Act.

However, the Mental Health Act—here is a real problem—is daily ignored and violated by the psychiatrists of this province. The enforcement provisions are weak. They do not work. It is virtually impossible to ensure that the rights protections it contains are provided, and that can be documented from many sources, as I have indicated in your written materials.

The major concern of our constituents about Bill 109 is that it has even fewer rights protections. It has a fine for stopping an advocate from seeing somebody. It has a fine for lying about somebody's previous wishes. That is it. The concerns are that, as good as this act looks on paper in

principle, in fact it is going to be ignored, violated and disregarded in exactly the same way the current Mental Health Act is. We want you to consider seriously including much stronger enforcement provisions in this legislation and, at the very least—and it is least—adding a provision similar to that in the current Mental Health Act which makes it an offence punishable by a substantial fine to violate any provision of the legislation.

One of the main problems with the current Mental Health Act, which we again expect to see reflected with the new legislation—failure in practice, again not in the legislation—is around determination of competency to consent to treatment and, for that matter, other competencies. That is, of course, the very heart of this legislation. That is what this legislation is all about: making decisions on behalf of incompetent people. But first we have to know who they are.

#### 1420

The current pattern in the mental health system, and it is sometimes even stated as hospital policy, is to consider everybody competent as long as they are saying "yes" and to raise the issue of incompetency only when somebody says "no." That is not sufficient. We do not, as a society, allow doctors free rein to treat our children just because our children are incompetent. We have parents who say: "Wait a minute. I hear what the doctor says. There are other factors to consider. I weigh it and I make the decision that is best, overall, for my child."

We owe our incompetent adults the same dignity. That means not only that we must address the issue of competency and competency determination, but that when there is an issue, it must be carried out by properly qualified and trained people. The decisions must be made by people who know what they are doing. This legislation provides for people called "assessors" who will be trained, who will be certified, and we are very much in favour of that. It then totally dilutes that principle by, almost without exception throughout the act, saying that these determinations must be made by "an assessor or physician." I am sorry, but physicians have up to now done a very bad job of this. If you have a physician with the appropriate training and qualification, that is fine. A physician who is not trained as an assessor has no business being an expert under this act, and I would ask you to remove that word "physician" wherever it appears in that context.

I have two short final points. These are about areas of the legislation which make special provision for psychiatric patients. The first is in Bill 108, section 15. It provides that when a psychiatric patient is found financially incompetent under the Mental Health Act, the public guardian and trustee will automatically become statutory guardian of his property. No one except a psychiatric patient may be placed in that position. Anyone else who is found incompetent may refuse the statutory guardianship of the public guardian and trustee and may go to court and fight it out. There is provision in the legislation for emergency intervention, for temporary guardianships, and we believe that to be fully as adequate for psychiatric patients as it is for anybody else. We find totally unacceptable the stereotyping

of psychiatric patients as people whose property rights may be removed in a summary and demeaning way.

Second, both bills have sections providing that a court may award to a guardian of the person the right to admit someone to a psychiatric hospital against his will. Now, the legislation has provided some extra protection for psychiatric patients here by saying that this power must be specifically awarded by the court, but we see no rationale whatsoever for conferring it.

The Mental Health Act already contains, and will continue to contain, provisions for the involuntary admission of people who are likely to suffer serious harm or are likely to cause it to others. This provision, therefore, would only be used on people who are not likely to suffer serious harm or cause it to others and who therefore, in our view, should not be deprived of their liberty. We have even graver concerns that if such a power is granted, not only might it be exercised, but it might be used, frankly, as a club to compel behaviour in the community that the person does not wish to engage in, on the threat that he or she would be admitted to a psychiatric hospital if they did not do as they were told. We think that that is likely to result in people in the community having fewer liberties than those in the institutions, which would be a somewhat ironic result.

I am going to stop there. I am going to ask you to consider carefully the presentation later this week of the Ontario Advocacy Coalition and also, in particular, the presentations of all those individuals and organizations of individuals who are at risk of being found incompetent. There are many areas of controversy to be resolved, and I put it to you that the most important voices for you to listen to are the voices of the people who will be most directly affected by this legislation.

I am available for questions.

**The Chair:** Thank you. Each caucus has about three minutes. Mr Chiarelli.

**Mr Chiarelli:** Thank you for your submission. I appreciate your comments. I appreciate your experience and your perspective. I appreciate the fact that you are here, something that somebody else will not have the right to do; namely, 12 individuals from groups including Seniors Advisory Council for York Region, Metro Toronto Homes for the Aged, Ottawa Injury Recovery Clinic, Conseil national de bioéthique, Ontario Fibrositis Association, Informal Network of Parents, Health Care Aide Association of Ontario, Advocates' Society etc. They too have a perspective which I would like to listen to, because I would like to think I am looking at this process objectively.

Before the lunch break we had a group, the Ontario Coalition of Senior Citizens Organizations, represented by Professor Stephen Triantis, who went through the advocacy legislation. He thinks it is seriously flawed, whereas you think it could have some minor tuneup. Looking at it from my perspective objectively, I think there are some very serious concerns. Therefore, at the very least we should open the door to have additional people come in to talk to us, to assist me as a committee member, as an MPP trying to serve the people of Ontario, to make up my mind. I know that I have not, as Mr Malkowski said, heard all the

submissions, but I have heard a significant number of them and I have read a number of them, including the College of Physicians and Surgeons of Ontario and Dr Lowy from the University of Toronto, who says that we should be looking at a pilot project rather than coming holus-bolus into the legislation.

I just want to say that I appreciate your perspective. I appreciate what you are saying. I appreciate your advocacy. I think the time is right for it. Whether it is here two months from now or 12 months from now I do not think is significant in the context of getting it right and having at least a broad support on the part of the public so they know what they are getting into and they can be ready for it.

I am just going to ask you very quickly if you think that the advocacy legislation will impact in a very major way on senior citizens.

**Ms McKague:** Of course it will. I think senior citizens will be one of the groups most affected. That is not our area of specialty, but I am certainly aware from our contacts with organizations working with the elderly of the enormous number of people, for instance, in nursing homes, often in very substandard and unfortunate conditions.

I think we have to remember here that the Advocacy Act is not just to provide a tool for Bills 108 and 109. The Advocacy Act is a much broader scope than that. It is going to deal with the concerns of Bills 108 and 109, but it is also going to provide protection against abuse, against exploitation. It is going to provide voices that are badly needed for many people—elderly, disabled—who are in situations of abuse and exploitation. That is needed. That is not just needed today. That was needed yesterday and last week and 10 years ago.

**Mr Chiarelli:** But I have a problem as a member of this committee, trying to act responsibly and trying to come up with a reasonable decision, when I see the Ontario Coalition of Senior Citizens Organizations, representing thousands and thousands—I think they indicated they are an umbrella group representing 36 groups—and also last week a counsellor for London seniors and a number of other groups who are very concerned about this legislation, say, "Go back to the drawing board with it." So looking at it from my perspective, as people come through that chair, you have to understand it is very difficult for us to be so sure about it, looking at it as a member of the committee. So I hope you appreciate—

**Ms McKague:** I understand that. I have the advantage of having worked with it for 12 years.

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**Mr J. Wilson:** Thank you, ma'am, for your experience and bringing it before the committee today. It does worry me, though, and it does go back to our desire to see some more public input on this, because we do have groups that seem to know more about this legislation than we know or than we have been told today. For instance, I am still not sure what an advocate is, what the definition is, and it was brought up in this morning's hearings, a couple of groups saying, "What exactly is an advocate?" People seem to have different views on what exactly an advocate is going to do. There are some parameters, some things an

advocate must take into consideration, but there is no real definition of what an advocate is with any meat in it.

You mention in your brief on page 8 "assessors," and you say these would be people who have been trained and certified as having these skills, and we support that. Well, how do you know that? There is nothing in the bill that tells me—you say the assessor should not be a physician, so who—

**Ms McKague:** No, no. I did not say that. I said that being a physician is not enough—

**Mr J. Wilson:** You said it is watered down.

**Ms McKague:** A physician with the appropriate training is quite acceptable. I have no problem. But assessment of competency is not a medical task, and being a physician is simply not enough to accomplish that task.

**Mr J. Wilson:** In your opinion, who are these assessors going to be? Specially trained physicians, perhaps?

**Ms McKague:** They might be physicians. They might well be other people. They might be social workers. They might be psychologists. They might even be lawyers.

**Mr J. Wilson:** Who certifies them?

**Ms McKague:** This is something that has been discussed as progress of the legislation went on. There are certainly some ideas. I do not believe that I should speak for civil servants with whom I have talked about this. I can tell you that the ideas that have been put to me are ideas of which I am very much in favour. The model of competency determination is one I like very much, and I would recommend to you as a source on that, although it is fairly heavy going, the Weisstub commission report, the inquiry into mental competency—

**Mr J. Wilson:** Yes, I have looked at it.

**Ms McKague:** —which talks for 500 pages—512 pages I think—about what constitutes competency. The fact that it took 512 pages to talk about that is some indication of the complexity of the task.

**Mr J. Wilson:** In light of that, it bothers me, not just in this area but in legislation, period, that we leave so much up to the regulations to be defined outside of the legislative body. As a politician, if this system goes wrong, I am going to take the hit for it, yet I have nothing to say about regulations. They always add the flesh to the bones on this legislation.

Would you prefer to see a definition or some fleshing out of what an assessor is, for example, in the act itself?

**Ms McKague:** I have some ambivalence, I must say, because on the one hand, of course, it is better to have things enshrined in statute where they cannot be changed at ministerial whim. One never knows who the next minister is going to be.

**Mr J. Wilson:** I have a good idea.

Interjections.

**Mr J. Wilson:** We will not go down that lane.

**Ms McKague:** On the other hand, as a hypothesis, let us suppose that what the government is saying is, "We really think Dr Jones is an expert in this area, and our intention is to get Dr Jones to train assessors." You cannot

exactly enshrine Dr Jones in legislation. It is a problem. It is a problem that I do not think is of significant weight to delay this legislation.

**Mr J. Wilson:** Okay. Thank you.

**Mr Fletcher:** Thank you for your presentation. A funny thing about being with this government is that I can look at our benches and know that at least 50%, 60% or 70% of our members were at one time advocates for some group at some time. I know that—

Interjection.

**Mr Fletcher:** Yes, even ministers. I know Marion Boyd was an advocate for single parents and also battered women. That is why I find it strange that Mr Wilson does not know much about advocacy and that more people would know more about that.

**Mr J. Wilson:** I do it every day of my life.

**Mr Fletcher:** As far as the legislation is concerned, if you feel that—

**Mr J. Wilson:** Mr Chairman, that comment is uncalled-for in the light of my comments.

**Mr Fletcher:** Do I still have the floor?

**The Chair:** Yes, you do.

**Mr Fletcher:** Do you feel there should be more in the legislation which goes towards that family support, that the family should be more involved in the advocacy or anything else?

Interjections.

**The Chair:** With fairness to the presenters.

**Ms McKague:** You have hit me on a point that is a very difficult one for me to answer, Mr Fletcher. Of course family support is highly to be praised and encouraged, and I think this legislation does that in many ways. It provides, for instance, that barring some choice to the contrary it is family members who will make decisions on your behalf. I am also very painfully aware of situations in which there is a great gulf between individuals and their families, and sometimes the fault is on one side and sometimes it is on the other. There are situations in which the family are the last people who should be involved in decision-making. I think this legislation strikes a fair balance.

**Mr Fletcher:** Thank you very much.

**Mr Wessinger:** Thank you very much for your presentation. What I was interested in is your statement that the present Mental Health Act is ignored. I assume, from the position you are looking at it, you mean it is ignored with respect to the rights of individuals.

**Ms McKague:** Absolutely.

**Mr Wessinger:** I would like you to elaborate a little more on the basis of that perspective, but is it also often ignored with respect to the question of admission, in the sense that you indicated that people should be admitted where there is a serious risk of harm? Is there also a problem on the other side, of psychiatrists not admitting people when there is a serious risk of harm?

**Ms McKague:** Absolutely. I might, perhaps, refer you back to a case I did about two or three years ago. It was an inquest into the death of a young woman who was 21

years old who died of taking 300 Graval tablets. The reason she took those tablets was that she had discovered that the only way to get into hospital was to overdose. They would not accept her in any other circumstances. At that inquest one of the expert witnesses called was the medical director of one of our provincial facilities. I asked him, in cross-examination, what it took to get admitted voluntarily to his hospital. He said: "Frankly, we won't admit you voluntarily unless you make the commitment criteria. We don't have room."

There are two factors, in my experience, which play into whether people do or do not get into hospital, and neither of them is what the legislation says. One of them is available beds and the other is the availability of community resources. If you, for instance, look at the commitment criteria in Saskatchewan as opposed to ours, Saskatchewan has a "best interests" criterion. You can be admitted to hospital against your will in Saskatchewan if someone feels you will benefit from treatment. Our criteria and Nova Scotia's criteria are very much "serious risk to self or others."

One would expect a higher proportion of commitments in Saskatchewan. In fact, in Saskatchewan some 5% of admissions are involuntary. In Ontario it is some 21% and in Nova Scotia it is over 30%. It has nothing to do with what our act says. It is, "Do we have room?"

**The Chair:** Thank you, Mr Wessinger.

**Mr Winner:** Could I just follow up on that? Basically, from those statistics, that would indicate that many people are admitted who ought not to be and others are not admitted who should be.

**Ms McKague:** I would say only semi-facetiously that perhaps we could solve the problems of our system if we let in everyone who wanted in and let out everybody who wanted out.

**The Chair:** Thank you, Mr Wessinger. Ms McKague, on behalf of the committee I would like to thank you for taking the time out this afternoon and coming and giving us your presentation.

**Ms McKague:** Thank you for your attention.

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#### ONTARIO NETWORK FOR THE PREVENTION OF ELDER ABUSE

**The Chair:** I would like to call forward our next presenters, from the Ontario Network for the Prevention of Elder Abuse. Good afternoon.

**Mr Butler:** Good afternoon. My name is Doug Butler and I am with the Ontario Network for the Prevention of Elder Abuse. I would like to present the people who will be presenting with me: Mrs Doris Baker, also with the board, and Mrs Elizabeth Podnieks, who is a founding member of the network.

Before I continue I have some small housekeeping to do in that I want the committee to pay more than normal attention to my words, not because of the content of those words, but I have a physical disability which causes my voice to sigh. Just in case some of you are thinking I may have slipped out at lunch time and hit the bottle, I wanted

to put that to rest right away. Going through parts of this legislation sometimes made me want to head in that direction; I cannot deny that for a minute.

In terms of defining elder abuse, I think its name says it all. It is primarily physical, financial, psychological and in a lot of cases just plain neglect. Our group was started over the last year, and the object was to get rid of elder abuse if we could do it. Our goals are listed on page 1 of the brief we presented to you and they are very simple: to educate both professionals and laypersons in elder abuse and what it is; to promote the sharing of information; to develop educational programs, and we have started that process right now by targeting in on the younger people to give them some idea of what it is going to be like when they become an elder so they will do things that will not harm them in the future. It is also to advocate for legislation and systems for both victims and their families.

We appreciate that these pieces of legislation were designed for lots of other people in the province than elders, but as far as we are concerned, it is a good start to combatting this problem.

That sort of leads me to a point that was raised earlier by Mr Chiarelli. Please forgive me, Mr Chairman, if I digress just a little bit. It seems to me that you as a group have to decide whether or not these bills are better than what we have now. If they are better than what we have now, it seems we should get them in and fine-tune them later. You could go on and on ad infinitum to find out the exact, perfect piece of legislation—guaranteed you will not find it.

In terms of the process today, Mrs Baker is going to deal with Bill 74, I will say something about 108 and we will both do something on 109. Then in terms of answering your questions later on, I am sure Mrs Podnieks will be able to help us there. Doris, you can start in.

**Mrs Baker:** I am Doris Baker, a social worker by profession. The Ontario Network for the Prevention of Elder Abuse supports the concepts of advocacy on both the individual basis and on a systemic basis. We also support the intent of the act to allow vulnerable adults to advocate for themselves.

There are several points we would like to draw your attention to as you consider these bills. The first is that appropriate standards be established for the selection, training and supervision of the advocates. It seems to be a bit of a mystery as to what that means as the legislation in its bill form has been presented to each one of us.

We also want to draw your attention to what will happen when an advocate intervenes. We hope that the advocate, in intervention, will be taught to deal in a manner of mediation, to support, alter and enhance the roles of the primary care giver, because many vulnerable adults, 80% of them, are cared for by family members. If one has ever experienced not being able to get out for a lengthy period of time—probably most of us have experienced the crying baby—there is somebody who will come in to help. In respite care for persons looking after older people, you sometimes have to book two years in advance to get respite from caring for a vulnerable adult, often one's parent.

We would suggest that some attention be given to advocates having access to places of safety they can recommend to abused elders, particularly the physically abused elders.

We hope that when abuse is identified, in incidents of neglect such as exploitation, psychological assault or physical harm, there is an exploration of the entire situation before recommendations for change are undertaken. We ask you to recognize that there could be a crisis situation at any time within the 24 hours and that advocacy services be available during a 24-hour period.

We ask to draw your attention to the fact that there are vulnerable elderly persons who have no homes. They are unable to read, do not speak English, and these people must have advocacy resources available to them by advocates who can respond to their particular needs, particularly if these persons are under the stress of physical abuse.

**Mr Butler:** In terms of Bill 108, our network appreciates that of many groups in this province, elders will anticipate their incapacity as much as most groups. We like this bill because elders will be able to designate in advance personal care and financial decisions should they become incapacitated in the future.

In terms of taking a final look at this bill, we would like you to make sure you consider some of the following points. The first one is that if the application for a guardian ever finds its way to the public guardian and trustee's office, we want to make sure that the people there who are looking at this application for guardianship are professional people who have some experience in the problem of aging, which a lot of people tend to overlook. We also want to make sure that professional people—social workers, gerontologists etc—are involved in applications for competency decisions and when they are judging people's capacity in terms of section 9 of this bill.

Next, in terms of judging people's competency, we find that only too often this job is being left to the so-called professionals and that the significant others in a person's life—be they relatives, mates or otherwise—tend to get left out of the decision. I think the committee has to look at the beneficial effect significant others could have in determining somebody's competency.

The next one has to do with clarifying the legislation with respect to the communication method that might be asked of somebody being judged—not only language. A lot of people, especially in this province, have different languages, but there are lots of incapable people, lots of elders, who just cannot communicate with any kind of language. You have to make sure that someone will be able to communicate in the medium of his or her own choice.

The next one deals with the courts in this process. I am sure the lawyers on this committee will not be very happy about this, but I am saying maybe you should think about getting the courts out of it altogether. As other groups have represented, not only is there a severe backlog of cases, but I do not think judges per se have any special competence in this area and I think you probably do need some sort of board or panel that is filled with people who do have a competence and a special understanding of elders.

1450

Last but not least, of course I think it is grossly unfair to expect that in order to get to the court stage, unless somebody is going to advocate for himself, which is highly unlikely, he is going to have to go out and pay a lawyer a big buck to do it. That is not right. That should not be.

I think it was the last bullet that really sorely tempted me to hit the Scotch, and that was the question of Ontario residence in the cases of guardianship of property. Take a look at section 5 and subsection 24(2) of the bill. They just do not make sense. This is the way I am reading it. Both of these pieces of legislation say in effect that if an incapable person is living in Ottawa, his psychiatrist brother who lives in Hull cannot be his guardian. That is wrong.

**Mrs Baker:** With consent to treatment, the network affirms the importance and essential nature of individuals making their own determination about which treatments to accept, but we ask you to consider the following points.

Adequate explanation of an intervention or procedure should be undertaken, again in a form of language that is understood by the person to allow an informed choice. We believe that elderly people, often having spoken English for a while, under stress, in their 80s, may revert to their primary language, and it is very important for them to be able to understand in the language of their choice what is being explained to them.

We think it would be wise for the consent to be obtained by the professional who will administer the intervention or procedure. We ask you to understand that elderly persons might have need of special consideration allowing for the possibility of a lowered threshold of cognition, reduced hearing, reduced vision or simply taking a longer time to make a decision. Implied consent is not acceptable. That is subsection 5(3), not subsection 5(2) that we put down, so were a little impaired at that time. But we ask you to consider those points as you think about consent.

I am sure we are all aware that ours is an aging population, and as a society we continue to undervalue the resource of older persons. As a society we continue to have a fascination with violence and a tolerance for violence. In fact, we frequently see violence as instrumental or entertaining. It was in the 1960s that we recognized child abuse as an entity that is not acceptable. In the mid 1970s into the 1980s we began to recognize wife abuse and work towards its eradication. In the late 1980s work has begun on recognizing elder abuse. It is now estimated that of persons over 65 years of age, 40 out of 1,000, or 4% of these persons, are abused. In these presented comments to the proposed legislation, we have attempted to draw to your attention the need to focus these acts on the prevention of abuse of elderly persons. The three of us would welcome your questions.

**The Vice-Chair:** Thank you very much. Each caucus has three minutes.

**Mr Poirier:** You talk about 4% being abused—no more?—and you talk about physical and emotional abuse, I presume, of all types?

**Mrs Baker:** Correct. Abuse is a broad umbrella. Violence is one form of abuse, but there are acts of omission or acts of commission.

**Mr Poirier:** Thank God. I mean, I was afraid the percentage was going to be much higher, because if you are talking about one in eight or one in six women beaten—

**Mrs Baker:** One in 10. Perhaps Professor Podnieks could comment on that.

**Mrs Podnieks:** In the recent national survey on abuse of the elderly in Canada, 4% was the prevalent rate, but the report strongly indicates that this is underreporting. Because of the research methods we used, we had to eliminate many cases after the person had already admitted to certain types of abuse but simply did not complete the questionnaire. So it definitely is an underreporting. In a follow-up study of the original victims, many admitted to me cases that they had not given originally. So 4% is definitely on the very low side.

**Mr Poirier:** I think it is just the tip of the iceberg, is it not?

**Mrs Podnieks:** Oh, yes.

**Mr Poirier:** I think it is much worse than that from my dealings.

Were there any more specific points you wanted to change in some of these bills? I know you have said what you did not like, but would you want to make some specific points? Is there specific wording you would want? Would you be able to suggest that?

**Mr Butler:** One thing Doris touched on was this business of consent, which I looked upon when reading the legislation as being wink-and-nod consent. Subsection 5(1) of the bill goes to great lengths to list all the elements required for consent to treatment, and then it goes on to state in subsection 5(3) that the consent may be implied. There is just too much room for error when you have implied consent. It does not make any sense. If the area is worthy enough for a bill, surely the consent should not be implied. We think subsection (3) should be taken out entirely and something be added to subsection (1) to indicate that consent to treatment must be made either in writing, or by a recording or some other equivalent device.

**Mr Poirier:** I could not agree with you more. I think a lot of people have brought that point forward.

Coming from a riding that straddles Ontario and Quebec, there is the point of residency. I want you people to note that. A lot of families are cross-border. This gentleman is quite correct. If somebody lives in Hull, Quebec, and is the guardian of somebody from Ontario, it is the same family. I would really like you to look at that, because it does not make sense. Hell, if we are going to have free trade of goods and beer between Ontario and Quebec, damn it, surely when it comes to guardianship we can look at families who may live in Quebec and vice versa. I find there is absolutely no room in 1992 for that to be the criterion to disallow that type of person to act as a guardian for a member of the family. I would respectfully ask my colleagues to look into this and eliminate that.

**Mr Chiarelli:** Last week we had the question of those under 16 years of age. If a health professional was unable to decide one way or the other whether that under-16-year-old was able to give consent to treatment, legal counsel indicated there was a legal obligation on the part of that health professional to call in an advocate, but there was no legal obligation to call in or inquire of a family member who might not be there at the crisis. If there were an elderly person who found himself or herself before a health professional under circumstances where the health professional could not determine the competence of that particular individual, do you think there should be an equal obligation on the part of that health professional to contact the family as well as contacting an advocate?

**Mr Butler:** Oh, absolutely.

**Mrs Baker:** I would like to respond to that one as well. I believe a great debate goes on all the time in an attempt to make determinations between delirium and dementia. You could have a demented person who has a little delirium, but if you can clear up the delirium, the dementia may not be so bad and the person can make his own decision.

**Mr Chiarelli:** You would like to see something that indicates there is an obligation on the part of health professionals to contact the family as well as an advocate?

**Mrs Baker:** Yes, the reason being that to make those determinations about delirium and dementia, as I understand it one needs to know the prior history of the person: Is this a sudden onset or a long-term development? Have they recently had surgery and gone a little strange after the anaesthetic? We need to hear from the family or the very important persons in that person's life. The VIP may be the neighbour or the barber or somebody who has had an opportunity to interact with this person. They can provide information different than what one is going to get in an assessment at the bedside.

1500

I would like to hitchhike if I may on to this concern about the cross-border business. It seems to me rather paternalistic, or maybe it is maternalistic, or maybe it is parental or something in this day and age. I wonder why, if a son is living in Australia, this government of Ontario should make a determination about the availability of that son or daughter. We do not know anything of his or her wealth or ability to travel here within a short period of time. Certainly, as we look at the map of Ontario and see how the boundaries interact with each other, to force a person to live in Ontario to be a guardian or a conservator seems rather strange.

**Mr J. Wilson:** I do appreciate your comments. Mr Butler, you began by saying, and we agree, that the principle of advocacy and the principles in the bills are good ones. I would even agree they are long overdue to put into legislation. But you know as well as I do that to put something in place and try and tinker with it later just does not happen. It takes years to get a piece of legislation back on the legislative agenda to even try and revise it. We are trying to tinker with it now to get it right.

That leads me to your suggestions about one of the major problems here. Actually, your suggestions are major overhauls of what we have got in front of us. Even the simplest

sentence—which would be to allow significant others' input into the decision-making of competency, into that determination—is a huge issue. It is a balance-of-rights issue that we have been dealing with for the last week and a day and could spend a significant amount of time on. I think are we going to have to change this legislation, because it just does not do it as it stands right now. Major issue: getting the courts out of the system—an absolute, major overhaul of the legislation before us, whether you meant that or not.

I am going to ask you a question that I have asked other groups, because I am taking some heat in my riding. For instance, I badly need a haemodialysis machine in my riding; I have hospital beds closing at an awful rate. People ask me in all seriousness, and I do not think they are just playing devil's advocate, whether we should be spending, as the public guardian trustee says, some \$46 million, it could be, for this legislation to be implemented.

Ms McKague, prior to you, intentionally or unintentionally, talked about the fact that the reason we have two interpretations of the Mental Health Act is lack of community resources and the number of hospital beds. Now you talk about the need for respite care, that there is a two-year waiting list for that, and that places of safety will be required.

So I ask in all sincerity, should we be going holus-bolus with this legislation's implementation? Should we not be going for perhaps a scaled-down pilot project which would, I think, satisfy a lot of groups, until we see how this legislation works? Because the tremendous cost could mean that other community resources will not come on line. Something has got to give in the system. I am not setting you up, but if I am going to take the heat for this I want to know other groups are behind me.

**Mrs Baker:** I have not got Carla McKague's 12 years' experience—I only have nine in terms of working with this type of legislation. I sat on a commission where there was hot and heavy debate about who could make such decisions and who could not. I think we are dealing with ethical matters. Who has the right to have an extended life and a good quality of life? Is it the 42-year-old person who needs the dialysis machine, or is it the 84-year-old person who needs the dialysis machine? I do not envy the doctors in acute-care hospitals having to triage their judgements as people come in.

I think you are asking a very basic question. We do not revere elders in our society; they are not people of worth. Our whole organization is geared towards these older persons being seen as persons of dignity, and persons to be able to hand on some information from a broader perspective. The dollar-driven economy is the one I guess we all know.

I do not know if Doug has an answer. I do not.

**Mrs Podnieks:** I do not know how much you have involved seniors or older people in your deliberations here. I think if you were to involve them you would find that all they want is a decent quality of life. They are not asking to take up your hospital beds. They are not asking you for dialysis. They would be the first ones to say: "No machines, no machines of any sort. Just let me stay in place, age in place." I think you would find them to be extremely

reasonable in terms of who shall have what of the pie. They are not asking for a lot of extravagant services.

**Mr J. Wilson:** These are elderly people in my riding. I consider it a form of elderly abuse, abuse of elders, when a state that pretends to provide services to people—the big lie we have lived for years—cannot provide a haemodialysis machine or a hospital bed when these people have paid taxes all of their lives and are entitled to it.

**Mrs Podnieks:** If they want that, but a lot of them will opt not to have it. The same with chemotherapy. A lot of older people will say: "Thanks, but no thanks. Keep me comfortable, keep me at home. Let that 20-year-old leukaemia patient have the drugs."

As I say, I think it comes back to involving these people in this process, involving them as advocates. I do not know who you are choosing here as advocates, but certainly they should be older people, and they should be of cultural diversity.

**Mr J. Wilson:** One last question on that. That reached the question of what an advocate is, though. An advocate cannot sway a person one way or the other into making those judgements.

**Mrs Podnieks:** No.

**Mr J. Wilson:** The way I thought I heard you was, if the elderly were involved in the Advocacy Commission, you would have different decisions than we have seen in the past, for instance.

**Mrs Podnieks:** No, no. That is another thought, that a lot of the advocates should be seniors, not professionals telling people what to do.

**Ms Carter:** I would like to address one or two points on page 2 of your presentation on the Advocacy Act.

First of all, you say appropriate standards should be established for the selection, training and supervision of advocates. I think the intention is not to specify all those points in the act, because the commission itself will be at arm's length from government and will itself make decisions of that kind. We are handing those decisions over to the people who are going to be more intimately concerned with it.

Your second point: Some abuse of people living with families and so on—and, as we know, 80% of all the people are cared for by relatives—will be due to burnout and strain on the part of people who are basically well-meaning and trying to do the best they can. We are trying to address that, not so much in this legislation, but we are looking at the whole question, as you know, of long-term care. That is being discussed in the community right now. There will be legislation. Questions like respite for care givers and so on will probably receive attention there, and I hope there will be more funds and more community effort diverted into that kind of direction.

Nevertheless, there are some cases of deliberate abuse where it is not just because of burnout, overload and so on. I am just wondering whether your paragraph there really covers that. Again, in your fourth point you say that where incidents of abuse and neglect are discovered, the whole situation should be looked into. I am just wondering what you would suggest in the short-term, whether you do not

feel that in cases like that something needs to be done urgently.

**Mrs Baker:** I think a place of safety for a person, if we are into physical abuse.

One of the strange things one finds—and I work in geriatrics and have identified situations of abuse; financial abuse, which is a very big one—is that the elderly person, the incompetent, decides not to take any action. I am going to generalize now, which is always a problem. How can I put this? There may be situations where the older person would say, “I would prefer to have my son tinkering around with my bank account than never to see my son,” the fear of loneliness and isolation.

This is why we are talking about: Let’s go take a look at the entire situation. Can we get in there and mediate? Is this a situation, for example, that having the public trustee in for a period of time would help regularize the situation? The thing I have to say is that there are not many Walton families around. We would like to think there are, but kids and parents sometimes do not get along together. That may be a surprise to this group, but I believe it to be true.

**Ms Carter:** It is obviously a very delicate point as to whether the person is better off with the family, or whether maybe the situation is so bad that something else is going to be better. I do see that there is a real difficulty there.

1510

**Ms Baker:** But I think an advocate in that situation would be advocating for what the vulnerable person wanted, so that the person can make a clear decision, “I prefer to stay in this situation.” A whole group of ethics is involved, and I think until we get working at it and until it settles down, then perhaps we will have some knowledge for you.

**Mr Winninger:** You certainly raised a number of concerns about Bill 108 that are worthy of consideration. I just wanted to address the last point, which requires Ontario residence for guardians under the act. It is the same sort of situation you have perhaps faced with executors as well, the administration of justice being a provincial jurisdiction. Ordinarily the province’s jurisdiction does not extend beyond the boundaries of the province, subject to certain reciprocal agreements between provinces, so if a non-resident trustee such as Mr Poirier suggested were to be appointed from Quebec, you would have certain problems with that.

How do you enforce accountability to the court here in Ontario where someone resides outside the province? You may be able to do that by the posting of some kind of security or bond. Then again, in certain cases that may be insufficient. I just wanted you to know that there is a reason for that, and that is simply because our court’s jurisdiction does not normally extend beyond the boundaries of the province. You do want to ensure that the court has a supervisory role over the guardian who is appointed, because that is one of the important formal safeguards that is built into this framework.

**Mr Butler:** Is there some other way there can be some other body, other than courts, which takes on this supervisory function?

**Mr Winninger:** This is where Mr Fram might come in.

**Mr Fram:** We would love to have you aboard, but section 96 of the Constitution requires that jurisdictions that have historically fallen within the jurisdiction of federally appointed courts, like guardianship, like the parent’s *patria* jurisdiction, cannot be taken out of the courts. So it is generally the view that we cannot move guardianship to a board in Ontario.

**Mr Butler:** If courts are going to be kept around, if they are a necessary evil, is there some way that the people who are forced to go that route, and who obviously cannot afford it, can get compensated in some way by the government?

**Mr Fram:** No. There are provisions for legal aid. Hopefully, we can make a process that is quite accessible. As Doris knows, and Doris was a member of the committee that I chaired for quite a number of years, the procedure under the act for uncontested matters is as expeditious a process—where there is no objection—as can be designed, and indeed could be no simpler or faster if brought before a board. It is only the contentious matters that will ever get heard by a court, and there you are going to need legal representation, whether it is before a board or a court, in any event.

**Mr Poirier:** May I respond quickly. I understand your consideration, Mr Fram, but I want to make two very short comments on this. If the two ministries of transportation in Ontario and Quebec can have a reciprocal agreement where, if I get a speeding ticket in Quebec, it will hold in an Ontario court and be subtracted from my demerit points in Ontario, and soon I will be able to drink Quebec beer legally in Ontario, surely, damn it, in this consideration we can deal with having a bilateral agreement with Quebec if we have to; we can deal with a guardian who may live across the border in Quebec while his family is in Ontario.

**The Chair:** Professor Podnieks, Mrs Baker and Mr Butler, on behalf of the committee I would like to thank you for taking the time out today to come and give your presentation.

#### ONTARIO BOARD OF EXAMINERS IN PSYCHOLOGY

**The Chair:** I would like to call forward our next presenters, from the Ontario Board of Examiners in Psychology. Please identify yourselves for the record and then proceed.

**Dr Wesley:** I am Dr Patrick Wesley, the registrar of the Ontario Board of Examiners in Psychology. To my left is Dr Bruce Quarrington, the board’s consultant, particularly on this legislation. He is a former chair of the board and was a member of the psychology department at York University for 20 years. We would like to thank you on behalf of the board for the opportunity to appear to comment on this package of legislation.

In general, the board is very supportive of the provisions of all the bills before you. The philosophy of individual rights and choices is consistent with the philosophy of applied professional psychology.

We have confined our brief and we will confine our remarks to Bill 108. We are the regulatory body and we feel this is the appropriate one for us to comment on. In

particular, we will be focusing on suggestions on the issue of assessors and assessment as the substance of our remarks, as it forms the substance of our brief.

It was interesting that the issue of competence of assessors was raised by the presenter from the Advocacy Resource Centre for the Handicapped, among many other very appropriate points with which we find much to agree.

The board of examiners is the statutory body under the Psychologists Registration Act, and we have regulated the profession of psychology and its practice for over 30 years in Ontario. There are almost 1,900 psychologists registered, and the number of registrants grows by approximately 75 a year. The extension of regulation to psychological associates, a new category of providers which will come under the Regulated Health Professions Act, will increase this number.

The principle area of expertise of over 1,200 of the registered psychologists in Ontario is that of clinical and counselling psychology. In addition, and relevant to this legislation, there are almost 100 additional registered neuropsychologists.

The Regulated Health Professions Act and the associated 21 professional colleges acts will give the public of Ontario broader access to the quality-assured services of demonstrably competent providers. The health care professions are given a common legislative framework and a uniform code of procedures for public protection. The stress is on the development of professions within a quality-assurance and competency-assessment model, and we would ask that this major transformation of health care professions in Ontario is kept in mind by this standing committee as it frames its recommendations for changes to the legislation.

We have followed the development of Bill 108 over the last few years with great interest. As I said in the beginning, the underlying philosophy is in line with the primary aim of applied psychology, which is to support and enhance the individual's capacity for autonomous functioning. It provides the means by which competent individuals may make their wishes regarding property management and self-care functional should they lose competence. Bill 108 also provides a system of protective services for individuals whose competence is at issue and where their competent wishes are not known. Playing a role in these services are individuals who may be assessors of the competence of individuals as defined by Bill 108 in its regulations.

Psychology, almost from its scientific beginnings in the early 19th century, has been concerned with the objective assessment of competence for specific intellectual and social functions. To the present day, the test instruments used for the assessment of a wide range of competencies have been developed by psychologists. Virtually every one of the instruments reviewed in the Weisstub report, for instance, has as its origin a research psychologist. The current practice of psychology by many clinical psychologists and all neuropsychologists is largely concerned with the assessment of competence of clients for the management of their affairs and for self-care. The referrals for such work are made largely by physicians in this province.

1520

Section 1 of Bill 108 defines "assessor" as "a member of a class of persons who are designated by the regulations as being qualified to do assessments of capacity." But in various sections of the bill, physicians are explicitly named as possible or, in some instances, as required assessors. Why should that be? The reason would appear to be to permit physicians to act as assessors without requiring them to meet the special training requirements required of other assessors. The naming of physicians may make sense, since there are a number of physicians who, by virtue of their training and experience, would be equipped to make competence assessments of strangers. It could also be argued that the additional training that most physicians would need in order to become competent in capacity assessments would differ in its extent and content from that required to bring other health care workers up to the ability to do assessments.

But what is surprising, and what does not make sense to the regulatory board that examines psychologists for their competence in a variety of areas, is the failure of Bill 108 to name psychologists wherever physicians are also named. A greater proportion of psychologists have more appropriate training and greater experience in the task of assessing the mental competence of strangers than physicians. This explains the material offered to you in section 5 of our brief, which begins on page 7.

May I also draw your attention to page 8 of our submission where it indicates that the special preparedness of psychologists to function as assessors has been recommended by the two committees which prepared the reports leading to Bill 108. Both the Fram report and the Weisstub report propose that psychologists be recognized as capacity assessment experts. On page 9 of our submission, the specific amendments requested are indicated. In summary, however, what our suggestions amount to in the brief is a request that psychologists be accorded in this legislation the equivalent status accorded to physicians.

Bill 108 prepares the way to recruit and recognize additional workers who, with special additional training, would qualify as assessors. With certain provisions, this is acceptable to the board of examiners. An exclusive position as assessors of capacity is not sought for psychologists alone. In the board's view, however, it is not sufficient to specify courses of training that must be completed successfully. There must also be provisions for regulating those assessors to ensure the public that their standards of work and ethical conduct will be maintained. On these matters, Bill 108 is silent.

The solution suggested in the board's brief is to amend clauses 83(c) and (d) to specify that assessors must be recruited from members of one of the health care colleges regulated under the Regulated Health Professions Act. In particular, we suggest that they might be best recruited from a subset of those health professions that have been given special recognition as diagnostic practitioners in RHPA. The controlled act of diagnosis is assigned overall to six of the 22 professions in RHPA. Four of them may communicate diagnoses relevant only to specific areas of the body: chiropractic, chiropractic, dentistry and optometry—

and there will be no prize for figuring out the points of the body. The other two professions that have diagnosis as a controlled act are medicine and psychology, and they are the only professions in which the controlled act of diagnosis has any relevance or even reference to mental states.

However, RHPA allows the delegation of any controlled act, including that of diagnosis, to other RHPA health care professionals. Thus, certain other regulated health professionals, for example nurses, with appropriate special training could also function as assessors, in our opinion.

A further benefit of recruiting named assessors from the RHPA colleges is that an already existing system of regulation could be used to ensure public protection and public assurance of competence in this vital task. We set that out on pages 5 and 6 of our brief.

Two other points: We have been considering thus far professional assessors who are to judge the capacity for property management and self-care of individuals who are strangers to the assessor. This is often a complex and difficult task. If, however, the individual whose capacity is at issue is one who is not a stranger but is a person that one has known intimately for many years, the judgement of capacity need not be so technical or demanding. As set out on page 4 of our brief, the board has assumed that subsection 47(10) of Bill 108 is in part intended to recognize that a grantor of a power of attorney might wish to have a particular trusted friend or relative perform an assessment of his capacity for self-care should this ever be at issue, and the presenter from the Elder Abuse Network made this point too. If this was part of the intention, then the board wishes to endorse that intent but to draw your attention to the wording of that subsection, which does appear to limit capacity assessments only to qualified assessors.

Finally, on the last page of our brief, we wish to raise the question of capacity assessments that resulted in finding the individual capable of management of property or self-care. It is suggested that all such assessments be recorded and filed with the office of the public guardian and trustee. The required filing of such reports would provide useful information in contested cases and should also in some instances prevent shopping for positive assessments of incapacity, a danger that we suspect others will bring to your attention.

With those opening remarks, I would like to thank you for allowing us to appear and say that Dr Quarrington and I are ready to answer questions.

**Mr Chiarelli:** Thank you very much for your brief and your comments. I think you are pinpointing an area of concern that a number of people have expressed. I have a couple of questions. First, have you endeavoured or tried in any way to find out either from any of the ministers or parliamentary assistants or the government what they are contemplating in the regulations for the definition of "assessor"?

**Dr Quarrington:** No, we have not, but the language of this section that speaks about assessors clearly paves the way for the creation of a new class of workers. This is what gave us alarm. We have heard of the possibility of this sort of thing discussed at a meeting of the Canadian Institute of Law and Medicine. A particular unit at Baycrest

was proposing to become a training centre for this new class of worker. That alarmed us. It sounds like an awfully expensive proposition to set up such a training program, and furthermore, to create a mechanism for disciplining such a group. It seems an excrescence when there are provisions within the health care disciplines for self-regulation in this particular area of functioning.

**Mr Chiarelli:** It seems to me on this particular issue the government wants a blank cheque. Under section 83, the regulation section, it says:

"83. The Lieutenant Governor in Council may make regulations,

"(c) designating classes of persons, including persons who have successfully completed prescribed courses of training, as being qualified to do assessments of capacity."

Clearly the government is contemplating something, clearly it is not telling you or me and clearly I am very suspicious when that happens. What we are really doing is delegating the right to a minister or cabinet to legislate something that is very important to people and professions without us having a clear indication.

I want to ask any of the parliamentary assistants or any of the legal counsels whether they are prepared to share, within the next couple of days, any draft regulations or any indications as to what they have in mind under clause 83(c) in terms of regulating the definition or training of assessors.

**Mr Winninger:** In regard to Bill 108, no.

**Mr Chiarelli:** There is nothing in draft form at the present time? You are saying no?

**Mr Winninger:** Nothing I have seen. I am saying we cannot be in a position to release such information to you in the next two days.

**Mr Chiarelli:** Can you tell us what you are contemplating by clause 83(c)?

**Mr Winninger:** No. The appropriate regulations will be drafted.

**Mr Chiarelli:** You expect people to come in and give you a blank cheque on the definition of "assessor," where you might be going out and training people and it is totally out of the realm of professionals or individuals or family friends of vulnerable people. Basically you are going to come up and dictate what an assessor is. That is what this section does.

**Mr Winninger:** I think "blank cheque" is an unfair characterization. I do not think anyone has any intention to dictate here. The appropriate regulations will be prescribed.

**Mr Chiarelli:** On what process? If it is not a blank cheque, what is it? Let the record show there is no answer.

**Mr Winninger:** I am not sure what answer you want.

**The Chair:** Would legal counsel like to respond?

**Mr Chiarelli:** I want to know what you are contemplating by this legislation which you are asking us to approve. That is a simple question. What do you mean by clause 83(c)?

**Mr Winninger:** I think the meaning of clause 83(c) is self-evident. It is to me.

**Mr Chiarelli:** Well, I am very, very slow. Tell me what it means. What training could you be contemplating there? And training of what people in what expertise with what background?

1530

**Mr Winninger:** It says in the section, "training to qualify to do assessments of capacity." That is the purpose of the training.

**Mr Chiarelli:** Are you going to take somebody out of grade 8 and train him?

**The Chair:** Perhaps legal counsel could clarify.

**Mr Fram:** To the first question Mr Chiarelli asked, no, we do not have regulations developed at this point. Yes, we are exploring at a very early stage, with some help from the Ministry of Health, the possibility of training people with background in assessments, what the possibilities are, what are the level of assessments we need for various purposes of the act, at least as a first level of easy, sort of black-and-white situations. There would, of course, be further references in greyer areas, but we are just at that point of early exploration of the nature of the training, the groups of professionals. Of course, we are looking primarily at regulated professions that would be competent.

You have to understand where we are now. Right now, the quality of assessments done for various purposes is at an atrocious standard. The variability is enormous. We want to get a much improved standard of capacity assessment across the province, available in every part of this province, which again is a major problem with psychologists not being available.

**Mr Chiarelli:** This is a political question.

**Mr Stockwell:** We pay the bureaucrats to answer questions.

**Mr Winninger:** He was not happy with my political answer.

**Mr Chiarelli:** You basically said you did not have an answer and the bureaucrat does. I want to know who is calling the shots. Do you know what you are doing?

**Mr Fram:** So that exploration is now going on. Nothing has been determined at this stage, but that is the kind of effort that is going on now.

**Mr Chiarelli:** Can I suggest that as a matter of courtesy, professionalism and good common sense that the process include the health professionals who are likely interested in it, such as the psychologists and others, so that they do not come in discussing legislation cold and basically sitting back and waiting for something to happen without being involved in the process? Can you give assurances that these two gentlemen and their association will be involved in the process?

**Mr Winninger:** This kind of consultation that you promote has taken place in the past and it will take place in the future.

**Mr J. Wilson:** I was interested to hear the response, though, from legal counsel that they are primarily considering as assessors those persons already included under the Regulated Health Professions Act. Surely you have given

more thought to this. It is almost unbelievable, Mr Chairman, that they would think of going outside the regulated professions. I think it is a rather weak answer, especially now that, under the RHPA and through the good graces of the board of psychology, we have psychometrists and a whole pile of master-level people falling under that college. Certainly the availability across the province was greatly enhanced by that. In fact, I cannot think of any area of the province now where there would be a shortage of qualified people. It is distressing to learn that the government is thinking of creating a whole new bureaucracy and a whole new class of professionals out there. If that is not, Mr Fram, what the government is considering doing, then let's get that on the record. I mean, the word "primarily" from the Regulated Health Professions Act group, that phrase I find encouraging, but maybe you could clarify it.

**The Chair:** Dr Wesley wanted to respond first, I believe. No? Okay, go ahead.

**Mr Fram:** The nature of the training is to bring people who have some background in this to a common standard. We have not yet listed or thought about listing—you still have to examine who has the kind of background and what level the training will be to. We are not talking about massive years of training or a new profession. What we are talking about is training people with a background in the material to a common standard over a several-day period. We are not talking about huge new retraining programs for people with no background, or creating new professions.

**Mr J. Wilson:** When it takes 512 pages in one of the reports leading to the development of this legislation to discuss capacity, I think you would need someone with a very deep background in mental capacity determinations. You cannot train someone over one week at the Holiday Inn. It is not going to work.

**Mr Fram:** No, we are looking at people who have backgrounds to start with.

**The Chair:** Could we have a response from the presenters?

**Dr Quarrington:** It is just that the language of the act with respect to assessors does not stipulate that they are going to be drawn from the regulated health professions, and it implies that there is no particular concern for background. The other comment I wanted to make is that psychology has been involved in the workings of the Fram committee, in preparing an earlier document. It has served on the Weissstut committee. Those two reports found classified psychologists as expert assessors. Then, suddenly, the bill appears and there is no mention of psychologists. Something happened between the consultative work in those first two sessions and the production of the bill which puzzles psychologists.

**Dr Wesley:** If I may also add to that, one cannot become registered as a psychologist, or in the new category of psychological associate, unless there have been graduate courses successfully passed in the area of tests and measurements, assessment techniques, statistics, normal adult development and the fundamentals of adult psychopathology, which five are the pillars on which the concept of mental competency assessment is based in the psychological

literature. To suggest that it might be possible to take someone without that kind of preparation and turn him into an assessor is flying in the face of the 30 years' experience we have had in registering and regulating the very professionals who developed the concepts of the assessment of competency in the first place.

**Mr Winninger:** I have two quick questions. First, in terms of your recommendation regarding clauses 83(c) and (d), that assessors be drawn from the regulated health professions, you may recall that among the designated assessors the Fram committee proposed were social workers. I put it to you that you may have someone with a master's or a PhD in social work who has worked with the psychiatric unit for years and who would have considerable qualifications to assess, say, someone's ability to deal with personal needs; maybe not to make these medical decisions that physicians can make or the kinds of clinical decisions you can make, but to make perfectly competent, adequate assessments there. Yet they do not come under the RHPA.

**Dr Quarrington:** Yes.

**Mr Winninger:** Your amendment would exclude those kinds of qualified individuals.

**Dr Quarrington:** Yes, I think it is critically important that they be regulated. If social workers were regulated, I would have no objection to their inclusion, but since they are not at this time regulated, that is the concern. We know that the disciplinary functions of the voluntary college are not meaningful at all.

**The Chair:** Dr Wesley and Dr Quarrington, on behalf of this committee I would like to thank you for taking the time out this afternoon and giving us your presentation.

**Dr Wesley:** Thank you for the opportunity to listen to you.

**The Chair:** Well said.

1540

#### CITIZEN ADVOCACY OF OTTAWA-CARLETON

**The Chair:** I would like to call forward our next presenters, from Citizen Advocacy of Ottawa-Carleton. Good afternoon. Please identify yourselves for the record and then proceed.

**Mr Hanvey:** Good afternoon. We are from Citizen Advocacy of Ottawa-Carleton. Joan Black is a member of our board. Brian Tardif is executive director of Citizen Advocacy. My name is Paul Hanvey. I am a volunteer advocate and at the present time I am also president of the board of Citizen Advocacy.

Joan will speak to you a bit about the concepts of vulnerability and empowerment and Brian would like to spend some time speaking about Citizen Advocacy of Ottawa-Carleton, what we do as an association and also a little about volunteer advocacy.

We are pleased to be here today because we have submitted a brief to you that is generally in favour of the legislation as it sits today, the advocacy legislation, substitute decision-making and guardianship legislation. Our primary interest of course is in the advocacy legislation and

our reason for being here today is, I trust, the same as yours, and that is to assist in whatever way we can to help you get the legislation as right as possible.

You have before you a brief outlining our perspectives on the legislation. The brief was put together by an ad hoc committee made up of board and staff members from Citizen Advocacy, as well as representatives from the Canadian Mental Health Association (Ottawa-Carleton Branch); Disabled Persons Community Resources; Ottawa-Carleton Independent Living Centre, and the special needs forum of the Social Planning Council of Ottawa-Carleton.

I will briefly state that while our brief is generally strongly in favour of the principles behind the legislation, we have raised some concerns and made a number of recommendations in the following specific areas: (1) the independence and the representativeness of the Advocacy Commission; (2) that the advocate's primary purpose should be to assist vulnerable persons as much as possible to make their own informed decisions; (3) issues around access to medical records and confidentiality; (4) the interaction and interrelationship between the Advocacy Commission, paid advocates, the public trustee, guardians and volunteer advocates; (5) the potential liability taken on by all advocates; (6) duties of disclosure and contradictions that we have noticed between the various acts involved; (7) review and follow-up of the legislation to enhance and ensure its effectiveness.

In the latter part of our allotted time we would be pleased to respond to any particular comments or questions about the brief. On that, I will give you to Brian Tardif.

**Mr Tardif:** Again, it is a pleasure to be here and I always enjoy any opportunity I have to talk about Citizen Advocacy. In Ottawa-Carleton, Citizen Advocacy has as a mandate to enhance the quality of life for people with a social or environmental limitation that results from age, disability or impairment, by matching those individuals in supportive one-to-one relationships with volunteer advocates from the community.

Recruiting people from the community to be volunteer advocates is what Citizen Advocacy does. We work with a wide range of people who have disabilities. Rather than get into labelling, I am just going to leave it there. But we do work with an extremely wide range and are probably one of the few organizations that does work with such a broad range of people.

The role of advocates is varied. The focus in terms of establishing a match between a volunteer advocate and a person who does have a disability is on the social relationship or friendship. We believe this enhances integration, develops empowerment and reduces isolation.

What we think happens, and what we know happens, as a result of forming these relationships is that a natural process of advocacy develops if and when it is needed. Sometimes just the presence of a volunteer advocate makes the difference. We have noticed that when we have matched a volunteer advocate into a one-to-one relationship with somebody who may be in a group home or some other kind of supportive living environment, not only does the individual the volunteer advocate is matched to benefit,

but often other people in the home benefit as well just because of his presence.

We work with people who live in a wide range of situations, whether they be group homes, nursing homes, supervised boarding homes, supportive independent living environments, or people who live independently or with other members of their family. Most of the people we do work with, though, are people who tend to live in environments where they are particularly vulnerable because they are dependent on others to meet their needs. Again, it is the presence of an advocate or the awareness of the connection to Citizen Advocacy in our community that proves beneficial.

I would like to take the time to provide an example of one of the situations that occurred recently in our organization and how it was resolved. This was a woman, a senior, who had been living alone, independently, in the community. She was in her late 60s. As the result of a sequence of events, she had been admitted into the local psychiatric hospital. Shortly after she was admitted she was certified. She was started on a course of drug treatment. This woman was matched with a volunteer advocate from the community who, I guess, just kind of monitored things to see how the treatment was progressing and, in the course of the next two weeks, noticed a significant deterioration in this woman after she had been certified and admitted to the psychiatric hospital.

Because the hospital was a short-term-stay hospital, it was decided a couple of weeks after this that the woman was going to need long-term care and was going to be moved to Brockville. There had been no consultation with anybody regarding this matter and this woman had not wanted to go. She was clearly able to say that she wanted to go back home. There was agreement, I think, with everybody concerned, including the advocate, that this person was not really able at this point in time to live on her own again, that there were certainly some difficulties, but that the move to a long-term psychiatric hospital, away from any contact with family and the friends she had established, was not in her best interests.

Through the work of this advocate and with the support of the staff at Citizen Advocacy, we were able to alter the decision of the psychiatrist so that he decertified her and she was able to stay in the community in a nursing home. Eventually, when she moved into the nursing home, she did recover quite well and decided that she did not want to go back home, that she really enjoyed the kinds of supports she was getting in the home she was in. That is volunteer advocacy and I think that is a good example of the kinds of things volunteers can do.

1550

Citizen Advocacy is not without its weaknesses, and I think Sean O'Sullivan, in his report *You've Got a Friend*, identifies that one of the weaknesses, among others, is that those most in need of advocacy maybe cannot access it through Citizen Advocacy because of our dependence on the volunteers from the community.

I think a lot of us who worked on this brief to you, and a lot of us who work in Citizen Advocacy, would agree with that. I think, as we would see it, there is a continuum of advocacy needs in the community. Citizen Advocacy

responds more easily, perhaps, to those people who are in the community, to those people who are more visible to us. The people who live in institutions, the people who perhaps are less integrated or more segregated from the community, are those people who are harder to access, both by volunteers and by Citizen Advocacy.

The focus of the legislation seems to be more on that end of the continuum, and I think what we have identified in our response is the concern that there needs to be a balance here. There is a role for volunteers in advocacy; there is a role for Citizen Advocacy; there is a role for the community. We feel it is important, in implementing the legislation, that the commission really try to take a strong approach to balancing those two needs.

So we have expressed concerns about losing the volunteer advocacy component. Friendship, supportive relationships, intimacy between two people are important, and out of that there is an actual advocacy outgrowth.

At that point, I am going to stop and pass it over to Joan Black, who, as Paul said earlier, is going to talk about vulnerability and empowerment and those issues of the legislation.

**Ms Black:** Good afternoon. I am very happy to be here. Today, listening to all of the presenters, as well as the people on the panel who have responses, both positive and negative, I am enthralled with your learned responses and must confess that I come from a very basic point of view, a consumer's point of view. So my comments will be very brief, appear to be less learned, but hopefully will be taken into some consideration.

When we were talking among ourselves around the table about the term "vulnerability," over and over again it became clear to us that although it is beneficial for certain segments of society to have that term, for people who already have been labelled as physically disabled, mentally disabled or who have a hearing or sight impairment, it is yet another derogatory term. However, we could not come up with a term that would be more appropriate, except to say that when the advocates, on behalf of people whom this legislation terms as vulnerable, help to assist them to become more powerful or—the current buzzword—empowered, I can see, along with the consumers with whom I worked, the term "vulnerable" being acceptable.

When we looked at the legislation from the point of view of a paid advocate entering a facility where a person with a disability was living, we were quite concerned about the access that the advocate appeared to have into records that would describe the condition of a person with a disability without the advocate having prior knowledge of this person. As a consumer who has had this experience herself and has talked to many consumers who have had these experiences, these kinds of judgements about people who already feel sometimes downtrodden can be very detrimental. What we would like to see instead is that when the advocate is acting on behalf of a vulnerable person, the advocate see the vulnerable person first and then make appropriate assessments and consultations with other people involved in his network of professionals or significant others.

We were also very concerned about the role of advocates who were acting on behalf of people in mental health

institutions. What is the role going to be for these advocates when interacting with the Ontario Ombudsman?

Last, my comment pertains directly to written responses to Bills 108 and 109. Although it may be self-evident through other presentations you have had throughout the hearings, it was very important for us to illustrate again that although we appreciate that the documentation through Bills 108 and 109 must be written, appropriate arrangements must be made for people who have to respond in other forms, such as larger print for those who are visually impaired, or tape—another way that people with hearing disabilities, as well as other disabilities that I have not illustrated, such as cognitive disabilities, would have access to these submissions that would be equally valid as written submissions.

Thank you very much for your attention.

**Mr Chiarelli:** First of all, I want to thank you very much for your brief. I appreciate the fact that you put considerable study into it. You indicate whom you have consulted with and that you have given serious consideration to the legislation.

I also want to say that I think you are a good example of what we have seen over the past week and a half, and that is that citizen advocacy is alive, reasonably well and growing in Ontario, and it is a very positive dimension. I think that is quite clear. What we are seeing in this legislation, I guess, is some effort to enhance it, perhaps institutionalize it, better fund it, provide better training and maybe give a little more leadership to that particular area.

I also appreciate the fact that you support the principles of the legislation, but I have some very particular questions to ask. I want to just read a couple of points in your brief before I ask the question.

On page 14 it says: "But while the role of the advocate vis-à-vis Bills 108 and 109 appears quite clear as stated above, that role as defined in the Advocacy Act is very unclear and will be defined by the commission. Perhaps Bill 74 should be implemented first and the role of the advocate clarified prior to implementing the companion legislation." That is point 1.

Point 2 is that on the same page you indicate: "Bill 74, the Advocacy Act, suggests there will be two classes of advocates, those who are paid and volunteers. The question and concern arose regarding the relationship between the two if both were involved with the same individual. The role of the paid advocate as defined under the proposed legislation (Bills 108 and 109) appears similar in many ways to that of a court clerk. The committee felt strongly that this role was inappropriate and care and attention is required to ensure this does not occur."

In the first example, you indicated—I am using the quote—"very unclear," and down here, "felt strongly." There have been a number of strong advocates, people who support citizen advocacy, as I think all of us in this committee do. But the issue is, how appropriate are the particular provisions of this group of acts, this legislation that we have before us?

My question is this: We have no idea what amendments are being proposed by the government. We in opposition can propose some specific amendments, usually not

accepted by the government side, so I am going to ask a hypothetical question. If the legislation, were to be passed as is, all of the bills, what is your comfort level in working with it as is and how serious do you see the problems being in working with the particular provisions as written?

1600

**Mr Tardif:** It happens that we assigned aspects of the brief to each one of us before we came down here, and the aspect you are asking about is the one I have chosen to respond to.

First of all, I want to respond to your questions around this section, because there was some real discussion around what we wrote here.

When we looked at Bills 108 and 109, again, the role of the advocate is very clear. It is a role of informing and reporting. Basically, those were the two kinds of activities that came up time and again throughout those two pieces of legislation: informing and reporting.

There was not a lot of emphasis placed on assisting people move through, and maybe that is not necessarily the role of the advocate in relation to those two pieces of legislation. But we felt, when we looked at Bill 74 closely, that the role of the advocate was vague; it was less clear than the other two. So we had some concerns about that. The concerns stem from the fact that if Bills 108 and 109 were implemented in concert with Bill 74, the resources of the advocates would probably be taken up almost completely by implementing and responding to Bills 108 and 109, and there would not be adequate resources left to respond to the demands that are going to arise as a result of Bill 74. That was where that concern arose and why we felt it was important to point that out.

As we have indicated, there are a number of recommendations that we have made in this brief. I do not think we would have made them if we felt that the legislation as it stands did not need some modifications.

**Mr Chiarelli:** If I can just sort of re-emphasize the question, can you live with it as it is, or would you find it more difficult than you would like to, as it is?

**Mr Tardif:** I do not know if I can answer that question for all of the people I represent. We certainly did not come to the decision that we could live with it as it was, but then the question was never posed.

What I would say is that the Advocacy Commission seems to have a great deal of influence over how the legislation will be implemented. Because there is a lot of uncertainty and lack of knowledge or understanding about how that is going to happen, people are concerned, and I think we would share those concerns.

**The Chair:** Thank you, Mr Chiarelli. Mr Wilson.

**Mr J. Wilson:** Mr Chairman, in the interest of time, I am going to pass. Thank you.

**The Chair:** Thank you. Mr Malkowski.

**Mr Malkowski:** I would just like to clarify two things. You said you were concerned about the access to files. The advocate would go in, but the advocate must have permission from the vulnerable person to read the files. That was one thing I would like to clarify.

The Advocacy Commission will decide the regulations in terms of what your concerns are, so do you have any specific recommendations that the committee could think about regarding the role and responsibilities of the Advocacy Commission?

**Ms Black:** Just to re-emphasize, the advocates who are acting on behalf of vulnerable persons have a positive perception of people who have disabilities. Often people who act on behalf of individuals with disabilities act from their own experience rather than considering the perspective of the vulnerable persons themselves. I think that is why Citizen Advocacy, at least in Ottawa, is such an effective model, because our advocates, although they may in fact be professionals in other terms, other than social work or the helping professions, come to serve the needs of a vulnerable person from the aspect of friendship. Therefore, the intimacy that is required and the respect that is required in dealing with people from that level is not forgotten.

**Mr Malkowski:** Would you agree that the Advocacy Act is important to protect the vulnerable person from abuses or exploitations or neglect?

**Ms Black:** I agree that it is an important step. It will require a great deal of visitation, perhaps first reviewing the legislation on a five-year basis; then I deem it important to revisit it frequently, because the situation and the way vulnerable people are viewed is going to change in society as we as consumers become more empowered.

**Ms Carter:** It seems to me that advocates, as envisaged under Bill 74, have two functions. One is to communicate with vulnerable persons and find out what their wishes are and attempt to follow them up. It seems to me that your concept of advocacy, the one-on-one volunteer, satisfies that requirement quite well. As far as I know, there is no reason under the bill why they should not do that. There is provision for people to be advocates on a voluntary and community basis.

But the other aspect of what they will be doing is to see what kinds of problems are arising in the community, which will suggest things that should be done, things that should be changed in order to overcome some of those problems. I am just wondering whether those one-on-one advocates will be able to do that kind of work and whether there is in fact room for both citizen advocates and paid advocates. I wonder how they would interact and how that would fit into your picture.

**Mr Tardif:** We asked that question in our brief, because again we do not feel it is really clear how the volunteer advocates will interact with paid advocates, how the volunteer advocates will interact with the Advocacy Commission. We ask those questions because we do not feel the legislation is clear, and whether it can be or not is another question. But again, it is drawing attention to this. It needs to be addressed as the legislation is either modified or as it is implemented.

You are also talking about two types of advocacy here. One is the individual advocacy or, as the legislation and the minister's background notes talk about it, case advocacy as opposed to systemic advocacy. Certainly there is room for both types of advocacy, without question.

**Ms Carter:** Maybe the act is not trying to cross all the t's and dot all the i's, but set up a situation which hopefully will develop and mature and the difficulties will be ironed out.

It also seems to me, in connection with records, that sometimes records will need to be used on an impersonal basis for the systemic advocacy. The fact that maybe the advocate would not know persons whose records they were looking at would not be relevant in that case because they might be using them more for statistical reasons.

**The Chair:** Ms Black, Mr Tardif, Mr Hanvey, on behalf of this committee I would like to thank you for taking the time out today to give us your presentation.

1610

#### EASTER SEAL PARENT ADVOCACY COMMITTEE

**The Vice-Chair:** I would like to call forward our next presenter from the Easter Seal Parent Advocacy Committee. Go ahead and have a seat, please. I want to thank you for coming today. Could you please give us your name and then start whenever you feel ready.

**Mrs Donald:** Thank you. My name is Luda Donald and I am the chair of ESPAC, which is the Easter Seal Parent Advocacy Committee.

The committee has filed written submissions dated 26 September 1991 and today. I have also given the clerk a summary of the oral submissions we will be presenting today.

The written submissions describe at length the difficulties parents and small, disabled children have in coping with the system they find themselves in and with their disabilities. Because of the time limits I have been given today in making my submissions, I will not go into these difficulties at length but hope your members will all find the time to read the written submissions.

Our submissions today are confined to children under age 16. I should say that I am also a parent of a disabled child and that all of the members of the committee are indeed volunteers and not paid. The children we represent are victims of accident; brain-injured; burn victims; amputees both by reason of accident and congenital conditions; cerebral palsy; cleft lip and palate; hydrocephalus; juvenile arthritis; muscular dystrophy; neoplasm, which is cancer in children; scoliosis, curvature of the spine; and spina bifida. These are the types of physically disabled children the Easter Seal Society represents. We are not the Easter Seal Society; you will be hearing from them later. We are the parents' committee who have organized ourselves with the blessing and hopefully the support of the Easter Seal Society.

The society serves approximately 7,900 physically disabled children in the province and provides services to those children and their families. Our submissions will be, as I say, confined to the 7,158 of these children who are under age 16.

Most of the disabilities are long-term and require ongoing medical intervention, therapeutic intervention, special education intervention. The categories I have mentioned all relate to physical disabilities, but some of these disabilities are accompanied by perceptual, intellectual, cognitive, learning or behavioural problems as well. The conditions themselves can range from mild to extremely severe.

We are making representations today in respect of Bill 74 and Bill 109. I should say that we are extremely disappointed, and that is an understatement, that children have not been included in social advocacy under Bill 74. We are equally concerned, and that is an understatement, to find ourselves and our children included in Bill 109, which we say is inappropriate for our children. We believe we are one of the groups that will be most affected by Bill 109 simply because our children are in and out of doctors' offices, in and out of surgery, in and out of physiotherapists' offices, speech therapists', and a host of other medical and health-related situations.

Dealing with Bill 74, we say that our children should be included, that children under age 16 should be included. We are not difficult to identify as vulnerable. You do not have to cast about to find a definition of "vulnerability" for our particular group of children. We can be identified by medical diagnosis alone.

Children who are disabled, no less than disabled adults, require social advocacy. We need systemic advocacy particularly because we find that the existing system of treatments and support services is often fragmented, inefficient and sometimes outright unavailable. This situation is described at length in the written submissions.

Our children, if I may put it that way, live with their parents in the vast majority of cases. Some of them live in institutions and some of them live in foster homes but most of them live with their parents. The parents of particularly severely affected children, and even those moderately affected, live lives that you, ladies and gentlemen, would find hard to believe, let alone imagine yourselves living. The physical, emotional and financial responsibilities are enormous when a child is disabled.

Parents must perform home care treatments: they are nurses; they are physiotherapists; they are special education teachers. They must perform many services which would otherwise be performed outside of the home and which need to be carried out in the home. Often one parent cannot work and therefore there is an added burden of financial problems.

The cumulative effect of the emotional, financial, physical stresses over a period of years sometimes results in a high incidence of marital breakdown. If that happens, then of course there are additional difficulties to be suffered by the family, by the parents, by the child. Of course, as you can imagine, in one-parent situations often the social system is strained as well with increasing need for social assistance, with legal aid services, with extra medical services in the form of psychological help to parents and children.

Parents do not have the time to advocate effectively on their own behalf. The only reason I am here is because my child, fortunately, is mildly disabled. They cannot be expected to advocate effectively and consistently. The problems with parent advocacy are also gone into at length in the written submissions which I have referred you to.

We find ourselves in a very anomalous situation. We say it is anomalous and it is unjust. Our children have not been included under Bill 74 and yet they have been under Bill 109.

Under Bill 74, of course, the consumers, the disabled, have representation on the Advocacy Commission and on the appointments advisory committee. Because children are not included under Bill 74, parents have absolutely no representation on the commission. They have no say, no contribution in determining how advocates are going to be trained, how they are going to be selected and indeed how the Advocacy Commission is to be run.

Yet under Bill 109 these same advocates will be intervening when a child is about to receive treatment. We find it absolutely unbelievable that this should have happened, and we certainly find it totally unpalatable. The parents are in the front lines of the treatment of these children, of our children. They want to be, quite frankly. What they need is support and what they need is a voice. We are responsible for the children's care. We love them and we are the first to know if there is something wrong in the system which delivers the care they need.

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If Bill 74 is indeed extended to include disabled children under age 16, we say that the act should be amended so parents representing the children and who are secondary consumers—and we are—have an equitably proportionate representation on the Advocacy Commission and in the selection process of the appointments advisory committee.

We do not wholly endorse Bill 74 as it is written. We say that if children are included, the provisions governing the accountability of advocates' rights of entry and access to records should be revised to accommodate the needs of these children.

We have not done an in-depth analysis of these particular areas, and the only reason we have not is because we were under the impression in September that these hearings would be going on forthwith and we simply did not have the resources to go into these areas. Should Bill 74 be amended, however, we would want to have some input before a first reading, before a second reading of this legislation. We would like to have some input as this legislation is drafted, and we say that parents and relevant health care professionals ought to be consulted before any amendments or revisions affecting children are made.

I then go on to Bill 109. Looking at the bill, as I mentioned before, we are extremely concerned. We do not think this bill is remedial in respect to the majority of the children we represent; we think it is invasive. We think as a result of this bill it has the unfortunate potential to impede treatment delivery, which already is questionable in our present system, it has the potential to severely disrupt and damage a parent-child relationship and it would place additional onerous emotional and financial burdens on families who are already stretched to capacity. When we look at the fact that we might have lawyers intervene on behalf of a child cared for and living with a parent and that perhaps that parent will have to bear at least a portion of the burden of that legal cost, from where we sit, ladies and gentlemen, it is difficult to believe that this Bill 109 would be introduced to cover our particular children.

Dealing with the principles in the legislation itself, we say that there is a crucial differentiating factor between adults and children, and that is that before any treatment is

undertaken in respect of a child, there will have been a consent by a parent. The parents, who love the children, who take care of them, who have consulted with medical practitioners, who have indeed been recommended a course of treatment—for example, often surgery is not an isolated act; it is part of a course of treatment—these particular children will have a parent who has consented to treatment. So when a child expresses a wish not to be treated, the procedure envisaged, which is the intervention of the advocate, intervention perhaps of a lawyer in the review board hearing and perhaps an appeal to the courts, is not investigative in our circumstances, but right off the bat it is adversarial, because there are very few parents indeed, having gone through the decision-making process to have treatment administered, who will then turn around and acquiesce and say, “Fine, my child doesn’t have the surgery; my child isn’t going to get this particular therapy.” This adversarial process has the awful potential of dividing parent and child. Remember, ladies and gentlemen, that these children are not going to be whisked away from the parent; they are going to continue living with the parent.

We also say that these procedures are indiscriminate and they apply whether or not the proposed treatment would constitute physical or psychological abuse of the child. We say that these remedies, which apparently are designed to prevent harm in an exceptional case, are imposed upon the majority, general population of disabled children and their parents, and the majority, general population is made up of people like me, people who are concerned, people who give up their livelihood to look after the children, people who are in touch with medical practitioners, people who are wanting to see a system improved for, in my case, my child and all the children I have met. These are the people who are the majority population, and what we are handed in 109 is a procedure which obviously deals with the exceptional case.

We say that it is the reasonable risk of harm or abuse from treatment and not the wish of an incapable child under 16 which should warrant and invoke invasive and adversarial procedures between custodial parent and disabled child. In other words, we say that whoever drafted this legislation has gone about it backwards. The wish of the child should be only one factor to consider in determining whether mental or physical abuse will result from treatment.

We do not say that the wishes of our children under 16 should not be taken into account, and most parents who undertake treatment have already dealt with that in one form or other. Medical people deal with it. But we say that the wish of the child should be one factor and the focus in invoking this rather drastic procedure should not be the wish of the child, but could there be physical or psychological abuse as a result of the treatment?

Even in the exceptional case where treatment may result in harm or abuse, we say that there should be an intermediate investigative and counselling procedure available to parent and child before they are plunged into the procedures of Bill 109. We say that the remedies for the child at risk for abuse from medical or health-related treatment could probably—and I say probably only—be best dealt with in legislation designed to address child abuse.

I go to the specific now. I take the example of the wonderful, caring parent whose child needs two surgical procedures, as mine did. I have a little boy who is five years old. He needed eye surgery and he needed spinal surgery. In my instance, the eye surgery was undertaken two years ago and he had spinal surgery last May.

You can see a situation where maybe the parent is overzealous or perhaps the doctors, the two specialists undertaking the surgery, are not communicating well and the spinal surgery is set for May and the eye surgery—which takes, by the way, a couple of months to recuperate from—is scheduled a couple of months down the road. I personally would say that amounts to abuse of a child, to insist that a child undergo those treatments so close together. That is my personal view.

If that kind of thing does amount to abuse, then what you have is a situation of not really an abusive parent, but perhaps a parent who is unsophisticated, has listened to doctors, and one doctor says you have to have this, the other doctor says you have to have that, and in these circumstances might, without consulting each other, simply arrange for these procedures to be done too close together.

Here is an example where perhaps intervention is required. But in this exceptional case, we say it is absolutely unfair and damaging for this parent to suddenly find an advocate sitting on his or her doorstep, an advocate talking to the child, a lawyer being dragged into this, a review board hearing coming up and possibly an appeal to the court, when perhaps the best way of resolving the situation is to have an investigative, intermediate counselling procedure before any such hearing is undertaken.

Ladies and gentlemen, those are all the major submissions I have. I have not gone into the full description of the lives of the parents and the children, and I can only repeat myself and hope you do read the written submissions, simply because I think that description might put into perspective the effect these two bills would have on disabled children and their parents.

**The Vice-Chair:** Thank you very much for that submission. Mr Chiarelli, please.

1630

**Mr Chiarelli:** Thank you very much, Mrs Donald, for taking the time to come and share your ideas and the ideas of your association. In fact when I look at your brief I note that you represent over 7,000 physically disabled children, and you have some serious concerns about this legislation. This morning we had a representative of the Ontario Coalition of Senior Citizens Organizations who also had very serious concerns about the legislation as drafted.

I was particularly interested in your understanding where you ask if you could be additionally consulted before first and second reading. You should be aware of the fact that Bill 74 received first reading on April 18, 1991, and second reading on June 10, 1991, Bills 108 and 109 received first reading on May 27, 1991, and second reading on June 20, 1991, and as I see the intention of the government, probably within four or five months this legislation will be law. It will be law with amendments unknown to us at the present time.

I understand your concern, because I have expressed that concern on several occasions to this committee, but I believe we have to step back and look at it without having a live shotgun at our heads with this legislation coming down the tube with some imperative I cannot understand, given the extent of concern of a lot of particular groups.

I have one question in particular, but I simply want to quote one thing from your brief before I ask the question. You indicate here on page 3, paragraph 12: "Bill 109, as drafted, has the unfortunate potential to severely impede treatment delivery; to severely disrupt or damage a parent-child relationship; to place additional onerous emotional and financial burdens on families who are already stretched to capacity."

I take it that this is the viewpoint of your association and your group and that you are representing them, and I ask you, if the legislation as drafted now is enacted, how would your group likely respond to that or how would you like the legislation as drafted? Is it acceptable or not?

**Mrs Donald:** Definitely not. Absolutely not.

**Mr J. Wilson:** Thank you very much, Mrs Donald. You raised the point that in your experience, and you are representing several thousand children, the vast majority of those children are looked after by caring and loving parents and that there is the possibility in this legislation, particularly Bill 109, of setting up an adversarial system between the parent and child with state intervention. Given that we have not seen, to date anyway, the studies or statistics that tell us as legislators that we need a system in place like Bill 109 for children, and the government claims it is not an adversarial system and that is certainly not the intention of the legislation, why do you think we have this legislation before us today?

**Mrs Donald:** I cannot go into the minds of people, but I would hope the government is aware that the disabled community needs support. As far as 109 is concerned, I have no answer, in that children are not included in 74 and they are in 109. In so far as the types of remedies that are set out in 109 for children under 16 are concerned, I can only assume that what the government would like to do is to protect those children who are at risk of abuse, but as I said, it has set up a piece of legislation which appears to be indiscriminate. So perhaps their intentions are good, but in my respectful submission today, the execution certainly does not match the intention.

**Interjection:** Touché.

**Mr Malkowski:** Thank you for your presentation today. Your concerns seem to be related to Bill 74 not covering those children below age 16, and I am just wondering if you feel the Child and Family Services Act under the Ministry of Consumer and Commercial Relations is not enough protection for children from abuse or neglect. Would that be sufficient to meet your needs?

Second, are there some kinds of resources offered within the disabled community, a way of sharing information with parents or your committee? Are you involved in any way with the disabled community in providing information, maybe as a resource type of centre?

**Mrs Donald:** Perhaps I will deal with the second question first. We have been set up specifically in respect of advocacy. That includes information-sharing to a certain extent. The information-sharing has been to date handled quite well by the Easter Seal Society, which unfortunately is presently finding it difficult to fund even its existing programs. That is the way of the recession. But we are an action group. We have at the present time limited our resources to looking at a few issues that appear not to be dealt with by other groups or by the Easter Seal Society. In so far as linking up with other disabled groups is concerned, we are always looking for partners—always.

In regard to the first question, the major thrust we would like out of Bill 74 is systemic advocacy. We see abuse of the children as being very important, but we find that those incidents of abuse may well be looked after under the present child abuse legislation or under amendments to the child abuse legislation. Our focus is on systemic advocacy because a lot of the problems that parents and children encounter are not a result of incompetent service, are not a result of people not wanting to help; they are a result of fragmented, overburdened systems that do not work very well at all. What we look to out of Bill 74 primarily is systemic advocacy. That systemic advocacy may also have to grow out of individual cases which will be handled under the case advocacy, the individual advocacy.

**Mr Wessinger:** I would just like some clarification with respect to this question of age of children being treated. As you know, under the common law right now a capable child under the age of 15 can consent to his own medical treatment. Are you saying that we should take away that right a capable child now has to make a decision with respect to medical treatment?

**Mrs Donald:** No, I am not suggesting that the common law be changed at all, with this caveat: Under the legislation, apparently the question of capacity and capability which has to be determined by the treating medical practitioner has to be—I am sorry, I am getting wound up in my own words. As I understand it, under the present legislation when a medical practitioner has to decide whether or not a child under 16 is capable, he or she must apply certain criteria. The criteria are to be determined by regulation. As a parent and representative of ESPAC, I cannot comment on that until, of course, the regulations come down. The worry we have is how easy is it for a child under age 16 to be deemed capable.

**Mr Wessinger:** Would you support some minimum age at which the advocacy rights could kick in?

**Mrs Donald:** That is a very difficult question. Again, the common law allows room, as I see it, for applying the criteria to an individual child. Some children may be very mature indeed at age 11 and other children much less mature at age 13. I would hesitate to nominate an age simply because I think it so depends on the individual child.

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**Mr Wessinger:** Certainly it is the intention to deal with the actual capability of a child, not his chronological age aspect, because it is quite clear that many 15-year-olds might not be competent and other 12-year-olds might be. It

depends on the individual child, and I think that is certainly what the intent of the legislation is, to look at the individual child's capabilities.

**Mrs Donald:** If that is the intent, I am not going to pass judgement on that on behalf of ESPAC until the regulations are in place.

**Ms Carter:** I am a little bewildered by your approach. It seems to me that what you are saying about Bill 74 contradicts what you are saying about Bill 109, because by definition the advocates under the Advocacy Act are supposed to get the wishes of the actual vulnerable person. Now, when you are talking about children, they are vulnerable, there is no doubt about that, but in most cases they have parents who are not vulnerable. They may be undergoing great stresses and strains, and obviously we should all sympathize with that, but they are able to speak for themselves. So that if advocacy were applied to children under 16 in the same way it would apply to people over 16 under the act, you would in fact be putting a wedge between parents and children in very much the way you are complaining would happen under Bill 109.

**Mrs Donald:** Not at all.

**Ms Carter:** Can you explain that?

**Mrs Donald:** If I understand what you are saying, Bill 74, as we read it and as it appears to be, would provide social advocacy. Part of that social advocacy is systemic. Although parents are not vulnerable in the sense the child is, parents do not have the time to advocate.

**Ms Carter:** In effect, you are splitting the two functions of the advocate, the one of speaking to the vulnerable person, getting his personal wishes, and the systemic one. I can see that as far as the systemic function goes there might be a place for that, but as far as the primary function of getting the wishes of the vulnerable goes, it seems to me that in the case of a parent and child where the child is the vulnerable person that is not appropriate.

**Mrs Donald:** I divide also the intervention of the advocate between the medical treatment—medical treatment is everything to us. There is not very much more that children and parents need out of the social advocacy apart from proper delivery of medical treatment, accessibility to it, special education, social and financial assistance where appropriate and so forth. These are the kinds of things parents and children need. So when I make that division, as I understand your question, I do not think I am being inconsistent. We say that consent to treatment is not the place for this sort of intervention. Consent to treatment is dealt with under Bill 109. Going back to Bill 74, though, we say that perhaps we might require less individual advocacy under that bill but we certainly do require systemic advocacy. In that sense, I do not think I am being contradictory.

**The Chair:** Mr Wilson, one brief comment.

**Mr J. Wilson:** I will pass, Mr Chair.

**The Chair:** Oh, thank you. Mrs Donald, on behalf of the committee I would like to thank you for coming today and giving your presentation.

#### ONTARIO ASSOCIATION OF PROFESSIONAL SOCIAL WORKERS

**The Chair:** I would like to call forward our next presenters, from the Ontario Association of Professional Social Workers. Good afternoon. As soon as you are ready, please identify yourselves for the record and then proceed.

**Ms Roher:** I am Susan Roher. On behalf of the Ontario Association of Professional Social Workers task force on Bills 74, 108, 109 and 110, which I chair, let me thank you in advance for paying attention to us after so many hearings, and now introduce our delegation: Doris Baker, Glenda McDonald and myself. Details about us appear on page 6 in what you have been given.

I will begin on the page entitled "Preamble." OAPSW has made prior submissions on substitute decision-making, competency determinations and advocacy, which appear in your appendices. Throughout the history of our profession, social workers have advocated for the vulnerable adult, facilitated the voice of the disfranchised and empowered the decision-making of the consumer. Central to the practice of professional social work is the involvement of the consumer. We have members throughout the human service system; for example, in health, social services, mental health, education, housing and corrections. Now that you have been preambled, we will move along quickly.

OAPSW supports Bill 74 in its sanction of advocacy on an individual as well as a systemic basis and its intent to remove barriers that inhibit vulnerable adults from advocating on their own behalf. We recognize the need for advocates to have relevant standards, experience and skills to ensure objective and realistic outcomes.

Further, we recommend that advocacy actions be based on an understanding of the vulnerable individual in the context of the situation and/or system which is perceived to be infringing on one's rights.

We recommend that advocacy efforts be mediative and non-adversarial to promote and strengthen the appropriate care-giving behaviours of the social and/or family support systems and to maintain these systems.

Further, we recommend that more detailed consideration be given to incorporating existing advocacy interventions into the new advocacy system. For example, many social workers utilize their expertise in advocacy in existing programs, and we indeed have heard from citizen advocates today as well.

We recommend that situations of abuse, neglect or exploitation be seen to require both immediate response and long-term solutions involving behavioural, community and organizational changes.

We recommend that implementors of the act consult professionals with demonstrated competencies in case and systemic advocacy—such as, by the way, social workers—for selection, training and supervision of advocates.

We recommend that in the recruitment and hiring of advocates attention be given to cultural matching and the distinct needs of culturally specific populations.

We recommend strongly that an accountability mechanism be developed to review the actions of advocates.

We recommend that evaluation of the advocacy system be driven by consumers and other stakeholders.

I would like to add one recommendation that occurred to us later. We recommend that someone who has the authority decide whether a person is vulnerable.

**Mrs Baker:** It is my opportunity to talk with you about the Substitute Decisions Act. We might subtitle this "How Steve and I Spent Two and a Half Years of our Tuesday Nights." OAPSW is in agreement with the principle in Bill 108, that of allowing capable persons to determine future treatment decisions should they become incapable. We further support this proposed legislation in its aim to protect vulnerable adults from financial exploitation, physical abuse and neglect.

But we urge the government and this committee to consider the following recommendations in relation to this legislation.

We believe that adequate provisions must be made with resources and personnel to undertake the services that are proposed. For example, we believe that there are now large numbers of people in institutions who would need to be assessed and have substitute decision-makers assigned to them prior to moving to community organizations. We would like to see that there is an acknowledgement to utilize the particular education and expertise of social workers for service delivery under this legislation. Social work was acknowledged in the Fram report; it was dropped in the Weisstub report. We do not know why. We believe that including social workers in the multiprofessional assessment of competency is essential. If you look at section 46, within the six component parts we talk about shelter, clothing, hygiene and safety. That seems quite important to the work social workers are frequently called upon to do.

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We believe in the multiprofessional assessment. We think this is such a serious event, to have someone's capability of making his own decisions taken from him, that no one profession should be allowed the responsibility to undertake that. We believe that family members and/or significant others should participate in these determination decisions. It is a known psychological fact that the things we are involved with are the things we commit to.

We believe there should be protection for the fundamental rights of the individual to make a decision that might be considered non-conforming. I guess we would call these people eccentrics, or having eccentric behaviour. We recognize that the education and psychosocial approach of our profession ideally qualifies us to assist in the proposed training of assessors. We recommend that all assessors complete a recognized training program and that a method for accountability be established.

Earlier today we heard from ARCH, supporting social workers. We heard Carla McKague speak on our behalf and we heard the psychology association speak on our behalf. As you are aware, we are not a member of the professions in the Regulated Health Professions Act, but that is another debate for the legislators, as we get our legislation.

**Ms McDonald:** I am Glenda McDonald and I am going to speak to the Consent to Treatment Act, Bill 109. OAPSW endorses the important principle of self-determination which underpins the Consent to Treatment Act. We also

recognize and appreciate the advantages of consolidating all consent-to-treatment legislation within one act. As well, we feel that legislation is important to ensure that advanced decisions on health care are respected and followed. However, we do have one recommendation, and it follows on the point my colleague has just made; that is, in considering the consent-to-treatment legislation, we recommend that active support for social work legislation is consistent with the spirit of this bill.

We wish to bring to the attention of the committee, although I was encouraged to hear that the committee is already recognizing it, that the current definition of "health practitioner" in this legislation would relate to those who are currently legislated under the Regulated Health Professions Act. Once again, social work is not regulated under this act, nor any other. Subsequently, the professional practice of social work could conceivably not be governed by this legislation. We would not wish to leave the committee with the understanding that social work would not seek consent to treatment in health care decisions in the course of our work. However, this omission continues to diminish the importance of the contribution of professional social work within health care delivery systems.

I am also going to comment briefly on Bill 110 in that it addresses the policies and procedures governing the use of representatives of vulnerable adults in the appropriate acts. It underscores the critical importance of the selection, reliability and accountability of all substitute decision-makers. It also follows that a viable monitoring and appeal system is required to oversee the decisions of designated representatives and the subsequent impact on the lives of those affected. Thus, we recommend that the social work profession be included as a clinical resource in assessing the need for and selection of substitute decision-makers and for consultation on accountability and review concerns.

**Mrs Baker:** In conclusion, in case you have not heard us, we have been trying to demonstrate to you the suitability of the social work profession's mandate, education and expertise. I believe we could play a pivotal role in the refinement and implementation of this legislation. We believe that Bills 74, 108, 109 and 110 each deals with very complex and very sensitive human decisions. We would like to stress the potential of family, friend and facility care-giving processes as they could underscore the human rights component of self-determination, informed consent and quality care.

At present, social workers in many facilities are providing a core service of interventions integral to the process of decision-making. On behalf of the Ontario association we recommend that social workers' practice, knowledge and skills be well utilized in the complex planning and implementation of the bills before you. We would be happy to respond to questions.

**The Chair:** Thank you. Questions and comments. No questions? Ms McDonald, Ms Roher, Mrs Baker, on behalf of the committee I would like to thank you for taking the time out of your busy schedules to come and give us your presentation today.

The committee adjourned at 1656.

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First Intersession, 35th Parliament

## Assemblée législative de l'Ontario

Première intersession, 35<sup>e</sup> législature

# Official Report of Debates (Hansard)

Tuesday 18 February 1992

# Journal des débats (Hansard)

Le mardi 18 février 1992

## Standing committee on administration of justice

Advocacy Act, 1991,  
and companion legislation

## Comité permanent de l'administration de la justice

Loi de 1991 sur l'intervention  
et les projets de loi  
qui l'accompagnent



Chair: Mike Cooper  
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# LEGISLATIVE ASSEMBLY OF ONTARIO

## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

Tuesday 18 February 1992

The committee met at 0938 in committee room 1.

### ADVOCACY ACT, 1991, AND COMPANION LEGISLATION LOI DE 1991 SUR L'INTERVENTION ET LES PROJETS DE LOI QUI L'ACCOMPAGNENT

Resuming consideration of Bill 7, An Act to amend the Powers of Attorney Act; Bill 8, An Act respecting Natural Death; Bill 74, An Act respecting the Provision of Advocacy Services to Vulnerable Persons / Projet de loi 74, Loi concernant la prestation de services d'intervenants en faveur des personnes vulnérables; Bill 108, An Act to provide for the making of Decisions on behalf of Adults concerning the Management of their Property and concerning their Personal Care / Projet de loi 108, Loi prévoyant la prise de décisions au nom d'adultes en ce qui concerne la gestion de leurs biens et le soin de leur personne; Bill 109, An Act respecting Consent to Treatment / Projet de loi 109, Loi concernant le consentement au traitement; and Bill 110, An Act to amend certain Statutes of Ontario consequent upon the enactment of the Consent to Treatment Act, 1991 and the Substitute Decisions Act, 1991 / Projet de loi 110, Loi modifiant certaines lois de l'Ontario par suite de l'adoption de la Loi de 1991 sur le consentement au traitement et de la Loi de 1991 sur la prise de décisions au nom d'autrui.

### ONTARIO ASSOCIATION OF DEVELOPMENTAL SERVICE WORKERS

**The Chair:** I would like to welcome the first presenters, from the Ontario Association of Developmental Service Workers. Good morning. As soon as you are comfortable, could you please identify yourselves for the record and then proceed.

**Mr Anand:** I am George Anand, founding president of the Ontario Association of Developmental Service Workers. Beside me is Mr Jerry Monaghan, one of our executive members.

We are a very young association and we have been in existence for the last six years. Our members provide direct care service at the most personal and intimate level to the people who are developmentally handicapped. Our members come from the institutional setting and from the community setting and include those who are working in the educational area.

Since we have come in, some of the foremost concerns our members have expressed have been around the issue of personal care, around the issue of advocacy and around the issue of substitute decision-making, because our members were left in a state of limbo where they simply did not know where to turn when they had to make day-to-day decisions regarding personal care of the people they were working with.

The first major workshop we organized was in 1990. Subsequent to that, we organized another workshop in 1991 where we invited representatives from different consumer groups, and along with that, we invited representatives from the different ministries to come together and discuss what is needed around the issues of advocacy and substitute decision-making.

What we heard was that the present state is very chaotic. It is doing much disservice to the consumers, to the practitioners and to the people who are left to take day-to-day decisions regarding the personal care. We also realized that enough studies have already been done. The last thing we need is another study, another pilot project which is going to delay the process. What we need is that something should be instituted right away. Then after that system is in place, what we are recommending is to give it another three years and then come and look back at some of the overlapping areas and how you can streamline the system, how you can further tune the system.

What we have indicated in our submission are some of the issues or concerns that were expressed in our two major workshops, because we did hear from the representatives from the association of aging. They were very concerned with why the role of the public guardian should be incorporated into the public trustee's office. Maybe there is going to be a conflict there. We also talked about the different models, the kind of model that Alberta is working with and another model that Australia is working with. We looked at all those different models. So there were those kinds of concerns expressed. In view of those concerns, we are indicating those concerns in our recommendations so that maybe we can come back after a few years' time and see what those overlapping areas are that we are creating, and once we identify those overlapping areas, then look at it and see what kind of system it is possible to create which can streamline the process.

Another concern we heard was that it is going to impose quite a burden on families from the legalistic point of view. But again, we heard that under the present Charter of Rights and Freedoms maybe that is the only way to go about it. We still do not have much evidence to go with, one way or the other, so we felt that the best recommendation we can make is, let something be in place. That is what we need very badly. Let's go for it and then come back. Maybe a standing committee can come back and look at the whole issue again and streamline the process.

Furthermore, the direct care workers who have been providing the personal care to the people who are developmentally handicapped are the very people who know the residents, the clients they are working with, on the most personal and intimate basis. These are the people who know what kind of environments the people are faced with in their daily lives and what some of the personal care

decisions are that they are capable of making in their daily lives and what particular kind of social context and environment is going to be the most congenial one to enable these so-called vulnerable people to make decisions.

First, we felt very strongly that we are the people who should be given some role in terms of assessing the functional capabilities of the so-called vulnerable people, because through their assessment then it can be judged whether they are capable of making certain decisions in their life area or not, or to what extent, or what kind of social context is going to be the most congenial one for them to make those decisions.

Second, we strongly advocated that our members who were working at the direct care level be seen as advocates, because these people are the ones providing 24-hour care. They are in a very good position to advocate on behalf of clients, provided there is no conflict of interest. We have our members working in different types of settings, so there is no need for there to be a conflict-of-interest kind of situation.

Our last recommendation is definitely to take into account the sociocultural aspirations of different ethnic groups so that any kind of diversities are fully incorporated into the Advocacy Commission itself.

**Mr Chiarelli:** Thank you very much, Mr Anand, for doing the research and preparation you have done. I am sure it is very helpful to all members of the committee. I gather, looking at your written submission and the comments you have made, that you are rather tentative or cautious about the legislation, so much so that you want a review after three years because there are elements of the legislation that you think may need review. There is uncertainty in parts of it in terms of how it would work in practice and you want a little bit of a safety valve or an insurance policy so that you can come back and take a quick look at this after three years.

You are not unlike a number of other people in the sense that they agree with the principle, the substance of the legislation, they agree with a lot of the particulars of the legislation, but they are a bit concerned about the process. As Dr Lowy has mentioned, he would like to see this legislation implemented, with some changes, as a pilot project. What you are saying is, "Give it a chance, but don't go too far down the road without reassessing it, because there are very serious concerns."

Another part of the process is simply to listen to the briefs and recommendations of people who come in here and simply make amendments that we in this committee think are appropriate.

So there are very serious process questions. I have been trying to wrestle with that process. Personally I feel that, based on the submissions that have come in, there are so many amendments which are being recommended that when it comes to clause-by-clause we will almost be re-writing the legislation and, in many respects, redesigning it. On the other hand, a number of people, such as yourself, have said: "Let's take a chance with it. We need something. Get it in now and we'll work the wrinkles out later."

Could you perhaps tell the committee a little more about your two workshops and share with us some of the

groups or individuals who participated in your workshops? Are there any of their concerns you can share with us?

**Mr Anand:** The two workshops we have had, the organizations that attended, we have had a representative from the association of aging, a representative from the Ontario Association for Community Living, representatives from different parents' associations, and along with that, we invited the spokespersons from different ministries who have been working in terms of grappling with these three issues for a number of years: for example, Mr Steve Fram, Mr Hugh Paisley, Mr Willson McTavish and Mr Michael McHenry. We invited them, and what we intended to do was bring them under the same umbrella with different consumer groups and try to come up with different kinds of options. What other different models exist at this particular stage? What other issues are we still faced with? What has already been done, and what are some of the fears and apprehensions that are being expressed by different consumer groups?

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What we realized is that it does not matter what kind of solution we are going to be able to come up with or what kind of option we are going to come up with; it is not going to satisfy every party. There are always going to be certain fears and apprehensions that are going to be expressed by one side or the other side. It does not matter what kind of models you come up with.

Moreover, some of the fears and apprehensions that were expressed were, for example, about the whole legislation being too legalistic. Why can you not put all the three pieces of legislation into one bill? Why do you need all these three different hierarchies in three different ministries to administer the bill when all three bills are so complementary to each other? We grappled with those. Then of course there were pros—just why do you need it?

Again, the kind of scenario we faced was that we did not have any kind of concrete evidence in front of us to say we should not go along with what is being recommended here. Then we looked at it.

The other option is to delay the process. Delaying the process is the last thing we felt anyone wanted. There have been years and years of study. There have been all kinds of advocacy groups and consumer groups clamouring to come up with some kind of solution to the dilemmas that families were facing, that consumers were facing and that practitioners were facing. The last thing, we felt, was to go for another study that is going to leave everyone in limbo, in the same status quo kind of situation.

Moreover, what we felt, and the fears and apprehension that were being expressed—there was no hard evidence in front of us. We did not know whether we could substantiate those kinds of fears and apprehension that were expressed. There was no concrete evidence, although we did grapple with the different models that were suggested at different places. But there were always pros and cons to the different models.

Our foremost concern with this is that there is a big vacuum that exists right now. There is enough pain and suffering already there. We need a solution right now. Let's

go with the solution and the intention of all these three pieces of legislation in terms of principle. I think everyone agreed with that. In our two major workshops everyone agreed with the basic principle, but it is how you are going to go about it in terms of the mechanism; there were differences around those areas. I guess our foremost concern was to have something in place and then come back.

**Mr J. Wilson:** Thank you, Mr Anand, for your presentation. I do have one quick question. It pertains to your second point, "The need to have one appeal process, making it non-legalistic, and timely to the extent possible under the Charter of Rights and Freedoms." What appeal process are you referring to there? What exactly do you mean?

**Mr Anand:** Again, I will go back to the workshops we have had. There is a certain appeal process under the consent to health treatment. What we are going to have is a particular board that is going to be set up under the Ministry of Health. Any kinds of decisions around the competency issue are going to be referred back to the board. That is on the health issue.

Then we have the personal care kind of issue. Any decisions of the families or anyone else who would like to dispute the personal care decisions under the guardianship plan where the public guardian's office is going to be involved, any kind of appeal is going to be done at a court level. Any kind of appeal process has to go to the court situation, the appeal against the public guardian's office that has to be instituted through a different appeal process.

Under the Advocacy Commission our understanding is that the advocate's role itself—if there are any differences on a decision or on the way the advocates are functioning, then those decisions can be appealed directly to the court. What we are saying here is—

**Mr J. Wilson:** It is part 2 of your remarks.

**Mr Anand:** Then we look at the personal care issues and the health care issues. Sometimes there are grey areas, and sometimes there is so much overlapping of the personal care and the health care areas. But then we looked at those personal care situations, and they deal with very basic freedoms. Those freedoms are accorded under the Charter of Rights and Freedoms. If those freedoms have to be taken away, then they could only be taken away through the formal legal process of going to the courts.

Maybe there is no other way of going about it. That was one of the concerns expressed, that perhaps it is going to be too legalistic. On the other hand, we also grappled with certain statistics that came to us. One of the statistics that came to us was that there have been so few decisions appealed under the present mental health system that perhaps that will not pose a problem; perhaps it will not be that expensive or it will not be that legalistic.

Again, in our minds—this was at a workshop—I think what we grappled with was that we wished we could come up with a certain common appeal process. Maybe the same appeal board can adjudicate on the personal care issues and the health care issues, or maybe there are certain common questions around the way the advocates are performing or functioning. But we discussed some of the basic legal principles; we discussed all that. So that question was still

hanging. That was still in the minds of the people in the workshops.

**Mr Fletcher:** What do you think about this committee process so far, coming in and giving presentations and making suggestions? Do you like this process? Is it a fair way of doing business?

**Mr Anand:** Yes.

**Mr Fletcher:** Do you feel rather insulted when you come here and you get asked a question about your workshops rather than what this bill is about?

**Mr Chiarelli:** That is a direct question.

**Mr Fletcher:** At least it is a question.

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**Mr Anand:** The reason we organized these workshops, first of all, is because there was concern among our own members that we were representing. The members, the direct care workers who have been working for years and years—my colleague here has been working at personal care, direct care, for the last 25 or 26 years.

**Mr Fletcher:** I could have got that information over the phone from you, though. You did not have to come all this way to tell me that.

I agree with what you are saying about the review. I think a lot of government legislation should be reviewed, and that is a commendable suggestion. Again, I remember one witness saying this is legislation that will evolve and can grow, if we keep looking at it over the years. But, as you say, let's get it going. Let's get it in place and then let's start tinkering with it if it needs tinkering with. But let's start the system going so that the people who need the service get the service, and then we can start looking at where the holes are.

Yes, there may be holes in every piece of legislation. I do not think we can always be right on. Look at what we have been stuck with over the years from previous governments that should have been reviewed many times. So I agree with what you are saying. I am not sure about whether along these lines, but I agree there should be a review on the legislation.

**Ms Carter:** I just wanted to follow up two of the points you made. One of them is that ethnic diversity should be taken into account. If you look at the Advocacy Act, clause 7(1)(f) does say we want to "ensure that advocacy services are provided in a manner that takes into account the religion, culture and traditions of vulnerable persons." I just wondered whether that does not speak to your concerns there.

**Mr Anand:** It does in a way, but from our point of view we felt very strongly, because a number of times when we look at the formal advocacy groups that are set up there, what we find is something very rare is those ethnic advocacy groups. Maybe part of the blame lies with their not being able to organize themselves to be able to speak on behalf of their own ethnic communities, and because they are not able to organize themselves, they do not find much voice in the formal advocacy groups that are there.

**Ms Carter:** I assure you that is something we are trying very hard to address in this and in other fields. I hope that your concerns there will be unfounded.

Also, I feel the three acts are integrated. You say that they should under one ministry, but the Ministry of Citizenship does have the lead, so there is a focus. The acts have been drawn up with regard to each other. They do come as an integrated package, and here we are in committee dealing with them all simultaneously, so I think we are all very well aware of that need to keep all this legislation in focus at the same time.

**Mr Anand:** Yes, it is great. Again, I will go back to some of the questions we faced in the workshops we organized. Actually, we were faced with a model, one that exists in Australia right now. The impression we got is that in Australia they have a common board. It is the same board that provides the personal care and the health care. Then the same board provides the advocacy function too.

The advocates go and visit whenever there is a question, when certain advice is needed. Again, there were certain pros and cons to each situation and to this particular process. Again, the pros and cons are going to be in any kind of model you may be able to come up with.

**The Chair:** Mr Anand and Mr Monaghan, on behalf of the committee I would like to thank you for taking the time out of your busy schedules and coming to give us your presentation this morning.

#### PSYCHIATRIC PATIENT ADVOCATE OFFICE

**The Chair:** I will call forward the next presenters, from the Psychiatric Patient Advocate Office. As soon as you are comfortable, could you please identify yourselves for the record and then proceed.

**Mr Giuffrida:** My name is David Giuffrida. With me this morning is Duff Waring. We are making a presentation on behalf of the Psychiatric Patient Advocate Office of Ontario. I have been legal counsel to that program since 1986 and am now serving in the capacity of acting provincial coordinator. The committee will have heard about the role of the Advocacy Commission in, among other things, conducting systemic advocacy. Mr Waring has been the systemic policy adviser with our program at head office and is now serving in the capacity of acting legal counsel.

In the interests of time we will not be speaking to all the points raised in our brief. There is an executive summary at the beginning of the brief that may assist the committee to follow our presentation. Of course we are able to answer questions with respect to points we do not specifically raise.

**Mr Waring:** The Psychiatric Patient Advocate Office was the first province-wide advocacy program in psychiatric hospitals in this country. Our program works for the rights of patients in Ontario's 10 provincial psychiatric hospitals. We have been doing the kind of non-legal advocacy envisioned by Bill 74 for the past eight years. We believe Bill 74 is urgently needed legislation to assist people with disabilities to become empowered to secure their entitlements and to resist abuse.

Our office is also one of over 30 member organizations of the Ontario Advocacy Coalition. Apart from our position

that the partial guardianship provisions should be kept in the Substitute Decisions Act, we agree with every recommendation in the coalition's brief to this committee.

We would like to emphasize the following issues on the basis of our experience. This committee may have heard of the large number of Ontarians who may meet the definition of "vulnerable people" and thus be potential clients of the commission. In our experience, only a fraction of our potential clients request our services. From 1990 to 1991 our advocates assisted 1,641 instructing clients out of a total patient population of 9,924. In short, only 16.5% of our potential clients request our services on an instructed basis. This committee ought to remember that advocates generally respond to the stated needs of their clients; they do not create them.

Another point we wish to emphasize concerns children in care. Bill 74 currently applies only to vulnerable people aged 16 or over. Our experience shows us that children in care also need advocates. In one hospital we responded to complaints that teenaged girls, at least one of whom said she was sexually abused at home, were stripped totally naked by male staff before being placed in a hospital gown and confined in a seclusion room. We conducted systemic advocacy in this case, which influenced a ministry decision to evaluate the ward and institute significant change.

**Mr Giuffrida:** I would like to address the issue of non-instructed advocacy. It has to be acknowledged that the cornerstone of advocacy as conducted by our program has been clients who are able to identify what their issues are and articulate them to the advocate. But it must also be acknowledged that some of the most vulnerable Ontarians are people who, perhaps because of mental disability, are unable to articulate any wish at all. None the less, they may be vulnerable to abuse and neglect.

For example, an elderly person may be tied in a geriatric chair in urine-soaked clothes, and because of staff shortages, may not be untied frequently enough and allowed to walk around the ward. As a result they may lose their power of ambulation. There are any number of issues we have been called upon to respond to where the client is not able to instruct us.

Another one concerns a man in his 90s with a pacemaker who was a victim of physical abuse by a young male nurse. The situation came to our attention and we worked hard to ensure that the family was notified, but we felt our hands were tied in pressing that the adult children of this patient be notified because of concerns that we not breach confidentiality.

It is important that when an advocate is possessed of information about abuse or neglect of a client who cannot instruct the advocate to share that information with third parties, the advocate not be at risk of running afoul of the large fine for breach of confidentiality contained in the act if he merely wants to share that information with appropriate responsible authorities.

It is also important in conducting non-instructed advocacy that the advocate have access to the relevant health care and other records pertaining to the client. As a rule with client-instructed advocacy, consent to those records will be only with the consent of the client. If the client

instructs us, "Don't look at my file," we do not, because we respect the autonomy of our clients. But for our most vulnerable clients who cannot instruct us, we are really at a serious disadvantage if we do not have access to relevant information in the record with which we could argue about their situation.

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Another point I would like to address concerns the provision in the Advocacy Act that allows for a breach of confidentiality if the advocate believes on reasonable grounds that the client may be at risk of causing serious bodily harm to another person. This is contained in subsection 30(4). It has long been the practice and written policy of our program that advocates have the discretion to breach client confidentiality not only in that situation but also in the situation where the client appears suicidal or expresses to an advocate a wish to cause serious bodily harm to himself or herself, particularly where that risk may not already be known to the treatment team.

We do not argue lightly for breaches of client confidentiality. As will be noted in my next point about the Freedom of Information and Protection of Privacy Act, we take client confidentiality very seriously. We acknowledge, however, that there are some circumstances in which the value of having a confidential conversation with one's client must yield to other interests. We note that the philosophy behind the Consent to Treatment Act and the Substitute Decisions Act is that while there is a presumption of competence, there is such a thing as a person who lacks the capacity, for example, to balance his cheque book, and we are prepared to intervene and get assistance from a third party. We must also acknowledge that someone's decision to harm himself may be a lucid, rational decision such as Nancy B made. On the other hand, it may not be. If the advocate believes, on reasonable grounds, that the person's desire to harm himself may not be a rational choice, the advocate should not be forced to tell third parties but should at least have the opportunity to tell third parties.

The next point I want to address concerns the application of the Freedom of Information and Protection of Privacy Act. It is not currently mentioned in Bill 74, but it has been my understanding in the past that the government might be contemplating listing the commission as a scheduled agency to the freedom of information act. There are many sound policy reasons why the general information held by the commission should be available to taxpayers so they can have a look at what the budget and policies and procedures are of the commission.

However, our concern is that the freedom of information act applies to personal information contained in the commission. It has been our experience that the freedom of information act can be invoked by third parties who are not part of the advocate-client relationship not clients to ask our program to reveal to them the contents of advocate-client files. We have had 80 such requests so far, each one on identical photocopied forms filed by hospital staff wanting to look in our advocate-client files. We have resisted these so far. Four are under appeal. Given the competing interests that must be reconciled under the freedom of information act about access rights versus privacy, I cannot say

with confidence now that the FOI act provides adequate protection to the confidentiality of advocate-client files.

There is such confidentiality provided in Bill 74 itself. There is a right of access to those files by the clients, as there should be. There does not also need to be a right of access potentially by third parties under the freedom of information act.

The next point I would like to make concerns Bill 108, the Substitute Decisions Act. As Mr Waring alluded to, my first point concerns the one area of our departure from the brief of the Ontario Advocacy Coalition. As I understand the reasoning of the majority of our coalition, by eliminating partial guardianship it would put the hard question to the judge: "Don't impose an order for partial guardianship; only make an order if you're satisfied the person is so incapable that you would make an order for global guardianship. You would determine they are globally incapable."

While I am sympathetic to their goal in ensuring that guardianship orders are only made as a matter of last resort so the state is minimally intrusive in the lives of vulnerable people, I do not believe this is an appropriate way to achieve that. The reality is that people are in fact capable in some areas of their lives and at times incapable in others. To repeal the sections providing for partial guardianship would introduce a fiction that if you are incapable in one area you are incapable in all of them. I do not believe there is a need for fictions in this legislation.

Finally, under Bill 108 we note there is a role for the public guardian and trustee to investigate allegations when a vulnerable, allegedly incapable person may be at serious risk of a compromise to his rights. There appears to be no corresponding investigative authority given to the PG and T. We believe that is an omission that ought to be rectified so that they have access to the allegedly incapable person and access to the records appropriate to the investigative role that is imposed on the PG and T.

**Mr Waring:** The final point we would like to emphasize concerns the consent to treatment legislation. This committee may have heard predictions of the large number of people who may resort to a review board to challenge a physician's determination of treatment and competence and thus delay treatment. In our experience in the 10 provincial psychiatric hospitals only 7% of admitted patients are determined to be incompetent to consent to their treatment. Of that percentage only 11% apply to the review board to challenge it. Of that 11% only 10% are successful. This suggests to us that the impact of the consent to treatment legislation in other health care settings will be equally small.

**Mr Giuffrida:** I should add before we take your questions that Mr Waring and I were able to hear some questions directed at previous witnesses this morning concerning proposed review of the legislation in the future. There is ample precedent for legislation being reviewed at some subsequent time. There was a three-year review of the freedom of information act, for example.

This is ground-breaking legislation dealing with important human issues. I am confident that if changes are needed in the future there will be an opportunity for those changes to be made. I note for example that there were

major changes to the Mental Health Act in 1986 and 1987. It is not too many years after that that Bill 110, one of the bills you are dealing with, makes some changes to the Mental Health Act to fine-tune it. I am confident that can happen with this legislation as it can happen with any legislation.

**Mr Chiarelli:** Thank you very much for your brief. It was very technical and practical and certainly comes from a lot of very worthwhile experience. I want to read very quickly, regarding Bill 74, section 1, what the purposes of the act are.

“(a) to contribute to the empowerment of vulnerable persons and to promote respect for their rights, freedoms, autonomy and dignity;

“(b) to provide advocacy services to help vulnerable persons,

“(i) make their own decisions, exercise their rights, speak on their own behalf, engage in mutual aid and form organizations to advance their interests, and

“(ii) bring about structural changes at the political, legal, social, economic and institutional levels.”

It appears to me that when you describe what your group has been involved in over the last number of years, that would properly describe what you have been doing. Is that correct?

**Mr Giuffrida:** Yes.

**Mr Chiarelli:** My next question is, what main functions or provisions of the Advocacy Act itself, Bill 74, will change or supplement or enhance what you are doing now? In other words, what are the pluses this act will do for you, having been in the field, having been fulfilling the purposes of this act as described, which has not yet been legislated?

**Mr Giuffrida:** There are significant portions of the act that extend access rights to the commission and its advocates that we have enjoyed in respect of patients in the 10 provincial psychiatric hospitals. We only function in those 10 hospitals. Since they are government-owned and -operated, the Minister of Health can and has administratively given us access to those hospitals, provided office space for us in those hospitals, and appointed us under section 5 of the Mental Health Act to give us access rights to clinical records in respect of our clients.

However, if we could not serve clients in other facilities or in the community under such an informal structure, access rights to clients and to their records need to be set out in statute. There is no statutory basis for our program now. I consider it an affirmation of what we do that the description of the role of the commission so closely parallels what I believe our organization does. But when you are designing a program on the scale of the commission, it is very appropriate to set the goals and values it is meant to reflect in the legislation.

**Mr Chiarelli:** But with respect to the boundaries of your activities at the present time, do you see this legislation significantly enhancing or empowering you to do more in the psychiatric hospitals?

**Mr Giuffrida:** It will achieve a number of things. Our program is currently a quasi-independent program of the Ministry of Health. I can report that the Ministry of Health,

for as long as we have existed, has taken seriously and acted honourably in respect of honouring the independence of our program and our authority and freedom to speak to the media and to speak to committees such as yours. However, advocacy must not only be, but be seen to be, independent. One of the things that would be achieved by the existence of the commission is declaring that our program would eventually move under it and have the structural independence that is ultimately necessary for an advocacy program.

1020

Our access to client records is currently broader than the wording in the act contemplates, which is why I made the point about non-instructed advocacy. In respect of instructed advocacy, we get our clients' consent to look at their clinical records or we do not look at them. But we are also able, under our appointment under section 5 of the Mental Health Act, to look at the records of clients incapable of instructing us without their consent. We are concerned that this access right we now enjoy be continued under the Advocacy Act.

We are also concerned that there be amendments that, as I noted before, ensure that when an advocate is aware of abuse and neglect of a person who is incapable of instructing and needs to tell a third party, it be provided in the act. Currently we have difficulty with that. There is information right now that we would like to share with responsible agencies where we really feel, because of the freedom of information act for example, that we might be on shaky ground doing it.

**Mr Chiarelli:** Have you actually drafted amendments to the act which would satisfy your needs?

**Mr Giuffrida:** I believe some of them are addressed in the Ontario Advocacy Coalition's brief.

**Mr Chiarelli:** Are the sections actually drafted or are just the statements and the substance and the principle of the amendments recited?

**Mr Giuffrida:** The coalition's brief contains throughout it actual draft amendments.

**Mr J. Wilson:** Thank you for your presentation. I know a couple of weeks ago we had an opportunity to discuss this legislation. I am curious: Do you have assurances that your program will be incorporated into the Advocacy Commission, or are you kind of in limbo?

**Mr Giuffrida:** I do not believe we are in limbo. We are functioning as we have since 1983. There have been statements at various times by government indicating that intention, but I think ultimately that question should be directed to the government.

**Mr J. Wilson:** It certainly would make sense to me. You would prefer that route, obviously.

**Mr Giuffrida:** It is the appropriate evolution of our program.

**Mr J. Wilson:** Just another curious point. At the very beginning you said hospitals have requests in for your advocates' client files. I believe you said that.

**Mr Giuffrida:** Hospital staff members.

**Mr J. Wilson:** Why would they want those? Just fill me in on what would be going on there.

**Mr Giuffrida:** The standard request is one in which a hospital staff member files a personal information request to see any place on any shred of paper in our advocate offices in which his or her name might be mentioned. It obliges us by the strict wording of the request to search perhaps 1,200 files that might exist in our office since we opened in 1983. We note in our brief that the 80 requests represent 19% of all the requests filed for the entire Ministry of Health in a comparable period. Given the small size of our program, it really is a flood of requests. It is difficult not to characterize it as harassment, given the amount of time it takes to conduct the searches.

Since the requester is not obliged to state the reason for his or her request I can only speculate. Staff may be concerned that something has been said about them by a patient to an advocate. Indeed from time to time that can happen. But if a statement is made, let's say a complaint, by a patient to an advocate and recorded in the advocate-client file, that statement sitting in that file can cause no prejudice to the staff member at all. If the patient says, "In addition, I want you to report this staff member to his or her employer for the purposes of an investigation and perhaps discipline," at that point the information could be used to the prejudice of the employee. But at that point they can get it from their employer. As long as it is just between the advocate and client there is no legitimate need for a third party to see it.

**The Chair:** There are four colleagues on the government side who would like to speak. If we could be as brief as possible and as focused, it would be much appreciated.

**Ms Carter:** You have raised some very crucial points in your presentation, one of which is this whole question of non-instructed advocacy. As you know, Bill 74 at the moment is premised on the idea that advocates only act on the wishes of their clients. The other possibility of course is to do what you consider to be in somebody's best interests without his instructions. That is not allowed for in this act.

Once we depart from that or if we did depart from that, we get on a kind of slippery slope. You have mentioned examples where an advocate might see somebody in dire straits and you would need to report so that it could be put right. But there is a sliding scale, as it were, of issues where you are more and more deciding on behalf of the person, and there comes a point at which the question arises: Should you be referring to a guardian, or who is going to make these judgements? I just wondered if you could fill in a little bit more how you see that whole problem being resolved.

**Mr Waring:** Certainly. One point that has to be emphasized is that advocates in our program are not substitute decision-makers for their clients, regardless of their ability to instruct. No one is more aware of that slippery slope than we are because we have been doing non-instructed advocacy off and on for the past eight years. While we do not take the position that our advocates can make decisions on someone else's behalf, while we do not do best-interests determinations, we would like to be able to alert appropriate

people when we detect very vulnerable people who are not able to ask for help, who are not able to instruct an advocate and ask for assistance. We would like to be able to point out to appropriate people when we find these patients in substandard conditions, when we find them in conditions of abuse and neglect.

Again, we have no authority to make decisions on their behalf, but we certainly feel we ought to be able to alert health care providers, family members, legally appointed guardians and other people in that person's life to get them to improve the conditions.

**Mr Morrow:** I want to thank you for that fine presentation. Once again this morning you have proven to me that the public hearing system works because you have made me think about something about FOI and I thank you for that. Would it make sense to include some sort of clause for FOI in these bills?

**Mr Giuffrida:** What we are recommending is a partial application of the freedom of information act to ensure the public's access to general information. I believe that cannot be achieved by anything but statutory means, either in the freedom of information act or in Bill 74. I do not have statutory language with me today, but I believe it would require an amendment to Bill 74.

**Mr Morrow:** Thank you very much.

**Mr Winner:** A number of family members of current or former patients in mental facilities have come forward and suggested that the empowering role of the advocate might lead to conflict between the vulnerable individual and the family and moreover the advocate and the family. I just wondered, in your eight or nine years of experience with working with families of schizophrenics or other mental patients, what kind of role you might foresee under this legislation for the advocate vis-à-vis the family.

**Mr Waring:** There have been many cases over the past eight years where we worked with family members in order to resolve the complaints raised by their children who happen to be psychiatric patients. If we are acting on an instructed basis, none of us has any problem with working with family members if we are instructed to do so.

**Mr Winner:** I see.

**Mr Wessinger:** I have a short question on subsection 10(7) of the Consent to Treatment Act. You suggest it is possible to modify this provision. I was wondering if you might elaborate on your suggestions in this regard.

**Mr Giuffrida:** We do not have with us today statutory language for that subsection either, but we have looked at various possibilities. It seems that the parameters one could work with in adjusting that section would have to do with the age of the patient, the degree of invasiveness of the proposed treatment and the kinds of rights advice that would be delivered. Need it always be face-to-face, onsite rights advice, for example? No one in our program, and I believe in the coalition, gets any comfort from the thought that a five-year-old could interfere with routine medical treatment. I would actually be surprised if that ended up being the interpretation and the application of that subsection, if it were passed into law exactly as it is worded. But we

believe there is room to fine-tune that section just to ensure that needed medical treatment can be given to young children while still safeguarding the rights of people who are faced with invasive treatment.

**Mr Wessinger:** Fine. Thank you very much.

**The Vice-Chair:** I want to thank you for that very fine presentation and for taking time out of your busy day to come down and talk to us today.

1030

#### CITIZENS' COMMISSION ON HUMAN RIGHTS

**The Vice-Chair:** The next group up is the Citizens' Commission on Human Rights. Good morning and thank you for coming. Before you start, if you could say your names for the record and then begin when you are ready. Thank you very much.

**Mr Dobson-Smith:** Wellington Dockery, Bob Dobson-Smith and Halina Cirillo.

I am going to have Mr Dockery read a statement to you to begin. It is fairly brief. It is about three pages and double-spaced. It is four minutes or so, and it gives a position we take issue with.

**Mr Dockery:** "I, Wellington Dockery, of 295 Shuter Street, apartment 810, Toronto, Ontario, do state as follows:

"That on June 1, 1989, I arrived at my apartment and it had been padlocked shut by my landlord. I could not understand why, as my rent for the month of May had been fully paid on time.

"As it was about 2:30 am June 1, 1989, I pushed the door in and went into my bed.

"Later during the night I was awakened by the police, who then proceeded to take me to Queen Street Mental Health Centre without giving me any reason why. I at no time resisted in any way, but I could not understand why they took me.

"Upon arriving at Queen Street Mental Health Centre, I was asked by a psychiatrist if I wanted to be admitted. I stated that I did not want to be admitted.

"The psychiatrist admitted me anyway, even though he knew I did not want to be there. No information was given to me as to why I was there. He wanted me to sign some papers and I refused to do so.

"I was escorted by two security guards to unit 1, floor 1. This is one of the admitting units in the Queen Street Mental Health Centre.

"Upon arriving in unit 1, I was told by the nurse to undress and put on a pair of pyjamas. I complied with her order as I did not want to have the staff forcibly remove my clothing.

"On June 1, 1989, I was found to be mentally competent to manage my finances. This assessment was done by another psychiatrist.

"On June 2, 1989, I was placed on a certificate of involuntary admission by yet another psychiatrist.

"On June 2, 1989, I was not yet informed of any rights I had pertaining to my being kept in the hospital.

"I was then told I had to take some psychiatric drugs, which I refused. In 1990 I obtained my medical records by filing a form with the Queen Street Mental Health Centre,

and in those records the psychiatrist states that if I refused my oral medication I was to be given intramuscular injections.

"The injections began on June 2, 1989, after I had refused to take the drugs orally and after I repeated that I did not want any drugs.

"I was held down by three attendants and a male nurse injected me in the buttocks. This forced treatment continued three times a day for one week. During this week I was kept in pyjamas against my will. I voiced that I wanted to leave.

"After a week of being brutally injected with drugs against my will I became physically overwhelmed by the continual forceful actions for refusing to take the oral medication and I eventually succumbed to orally taking the drugs, even though it was still against my will. By doing so, I wanted to at least stop the physical assault done to me on a routine basis.

"I was then transferred to unit 1, fourth floor, and I was held there without my consent, against my will, for another three weeks and then released.

"The adverse effects of these druggings left me with a partial inability to control my facial muscles and I could not speak properly for over six months. It has been over two years and I am now worried that some damage from this speech disability may be permanent. This impedes my ability to work as a car salesman."

I hereby state the above is true. I appreciate this opportunity to address this committee.

**Mr Dobson-Smith:** Mr Dockery's case is a very common case. We have several hundred of these cases currently. Our group, the Citizens' Commission on Human Rights, was established by the Church of Scientology in 1969. We have been involved for a couple of decades now and I have been in charge of it since 1972. During that time we have been involved in numerous submissions on an international basis regarding mental health law and its impact on consumers of psychiatric treatment. For example, many of the recommendations of the Daes report to the United Nations were from our international office.

We know there are three separate bills before this committee. We are mainly concerned with the consent to treatment legislation. We feel that the consent to treatment legislation is the basis on which the person and his decision-makers have access to view their position. The previous Mental Health Act of Ontario proclaimed into law in December 1987 guaranteed informed consent to psychiatric patients. Basically it just simply said "informed consent," which was never defined. It is currently abused, as we know with Mr Dockery's case. It has been five years since that legislation took place and it still occurs on a regular basis.

We have cases that as of three weeks ago told us they had never received any informed consent. They are on things like Prozac. After a week and a half on Prozac they attempted suicide. They did not know why. They had never been to a psychiatrist before in their lives. This is the kind of stuff we are dealing with. No one is viewing these medications; no one is viewing the subject of these medications. They are looked upon as a pill. Pills are sort of

okay in this society. They are on TV. It is a very subtle, blunt blow to the head.

I am attempting to arrange a speech therapist for Mr Dockery today. His condition could be caused by a baseball bat over the head, except that when medication does this over a period of time you cannot see any bruises.

We have uncovered hundreds of cases of not only lack of informed consent but actual forced psychiatric treatment. In our experience, forced psychiatric treatment takes place when a patient refuses the medication or procedure and hospital staff and psychiatrists feel it should be given, regardless of patient refusal.

Peter Breggin has been involved in this since 1962, when he graduated from psychiatry at Harvard University. He is head of a group in Washington called the Centre for the Study of Psychiatry right now. His contention is that these pharmaceuticals are used to make patients submit so that they are easily managed within a facility. That is basically the only reason they are given these.

Dr Heinz Lehman, a world-renowned Canadian psychiatrist who did the original research on the drug chlorpromazine, which was used in every single psychiatric hospital in this country, has this to say about it in his research, and it is used on people without giving them any information on it whatsoever:

"Many patients dislike the 'empty feeling' resulting from the reduction of drive and spontaneity, which is apparently one of the most characteristic effects of this substance."

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He also speaks of lassitude and compares the effects to lobotomy.

"In the management of pain in terminal cancer patients, chlorpromazine may prove to be a pharmacological substitute for lobotomy."

Yet this major tranquillizer has been broadly prescribed throughout the entire mental health system of Ontario and Canada.

Dr VanPutten, another researcher who has done extensive research on drugs, talks about haloperidol and chlorpromazine, which are the two most broadly used psychiatric drugs in facilities like our public mental hospitals. People had "exaggerated feelings of depression and unrest without any apparent cause" and there were "depressions, anxiety, ideas of guilt and suicidal ideas" in 61% of those people in the study; 41% were considered serious and followed a discernible pattern. They complained that the treatment was making them worse and that they had been much better before they had any treatment. They repeatedly demanded attention or a discontinuation of treatment.

Our contention is that major tranquillizers are used for management purposes in psychiatric hospitals and that a person must have the same informed consent for this, which we will outline here, as if he was going to undergo a heart transplant or brain surgery or anything else. The results can be disastrous and the same.

The consent must be written, informed consent that provides the competent patient, or his decision-maker if he is incompetent, with all the positive and negative aspects of all medication or procedures. For a patient to be competent, and this is what is missed—psychiatry itself, I think

we can all agree, is an inexact science at the very least. With the pharmaceutical substances that it uses, it can actually be dangerous. Prior to any psychiatric treatment, to be competent to consent the patient must fully understand not only the nature of his treatment—no one in this room could be competent to consent to any psychiatric treatment unless he understood the nature of the treatment and the nature of his illness. The psychiatrically defined symptoms that could be called schizophrenia, a nervous condition, some kinds of disorders etc could also be the result of a broken back, cracked ribs, something wrong with the central nervous system, a disease, anorexia, a blood infection or any of these many different things; there are numerous things. We want to see a complete medical examination done before any psychiatric treatment takes place to ensure that the person is not suffering from a physically treatable disorder or condition.

We believe no one can be competent without understanding the treatment and the illness. As well, the patient should first receive a full medical examination to ensure that the psychiatrically defined symptoms are not caused by a medically treatable illness or disease.

I have gone into a consent form here that is fairly lengthy and you can look through it. It goes into the reason for the treatment, the nature of the procedures to be used, the probable degree and duration of improvement or remission, the nature, degree, duration and probability of side-effects, significant risks etc. It goes into that in detail. This copy of the consent form is currently in use in California. It has been now for 14 years, since 1978 or 1976, I think. It is called the Vasconcellos bill. It is Bill 1039, state of California. It is the informed consent law. Basically it constitutes informed consent.

The reason we want to have written informed consent is because one psychiatrist or one practitioner will give a person a certain amount of information—it may be significant and it may not be—and another one, as in the case of Mr Dockery, might provide no information at all—nothing about the adverse reactions, nothing about anything that can take place.

We want to see a standard level of information provided, or else it is not fully informed consent. If you look through the actual precautions and things in the compendium of pharmaceuticals on these substances, these things should be printed in lay terms for a person. When he looks at this and says, "You're going to give me a pill; what is it?" and is told, "It'll make you feel better," that is no good. It is no good when that happens. This is the complication, and it happens in hundreds and thousands of cases. They have a tardive dyskinesia clinic at Queen Street to handle this. After they drug the guy for five years, they then send him to the tardive dyskinesia clinic downstairs for a lifetime of rehabilitation. It is completely unbelievable.

It should be the function of the advocate to consult with the person or the substitute decision-maker. The physician may go through the consent form with the patient or his guardian if requested to do so by the patient or the substitute decision-maker.

After his medical examination results are in, there has to be a 48-hour lapse for this person to absorb the information

on the sheet and discuss it with his family. This quick-fix treatment where he comes in, goes on to the ward, the bell rings and medication calls occur is quite unacceptable as far as an informed consent regulation goes.

I had a case in Hamilton who contacted me. She was in the hospital there. She said she did not want any medication. They come around, they ring the bell, they give her the medication. If she does not take it she gets injected, so she takes it. She holds out her arm. This is implied consent. She says: "I'm going to go now. I feel better. Thank you very much for letting me stay here. I'd like to go now." So she goes home, and then a nurse comes to give her the medication once a week. She says, "I don't want the medication any more." The police come to pick her up and bring her back to the Hamilton Psychiatric Hospital. This is not a political prisoner in a communist country.

The legislation that exists on informed consent is so inept, is so lacking in any direction, that there must be a firm outline, firm guidelines taken on it so that it can be defined and applied. Informed consent cannot be, "Well, it's going to make you feel better." That is no good.

I have also outlined here a complete medical examination. We have medical doctor advisers on our commission who have told us what would virtually diagnose everything. The main thing is a complete and thorough medical examination beginning when the guy goes into the hospital. This would include urinalysis and blood tests. There is a study that was done in Texas. We have never done a study here. It would be very interesting to have this committee recommend that one be done. They took 100 patients lined up at a hospital in Austin, Texas, who were readmissions to a psychiatric hospital; 87% of them had serious physical illnesses; 50% of those had illnesses like cancer that were undiagnosed, a cracked spine that had never been X-rayed and never been looked at, cracked ribs, heart conditions, thyroid conditions, food allergies, incredible skin conditions, dermatological conditions, things like this that were exacerbating the mental condition and were never even looked at. All they would do is pass out medication. That is what they did. That was their job.

We want to see this looked upon in this way. It may not be as bad as down there; I do not think so. I do not know if I am the only person, but I am probably one of the few people who have been to every single psychiatric hospital in Canada, from Newfoundland to British Columbia, in the last 20 years. I have seen just about every possible circumstance. Ontario does very nicely, thank you very much. We have nice settings and things.

The nutrition in food, though, is another curious area of contention. I had one case in a hospital who was in Penetang, who had never committed a crime, who was there because he was hard to handle in another institution. The doctor I brought in to do tests on him, nutritional tests, discovered that his diet consisted of six cups of sugar per day. His teeth were rotted out of his head. His diet consisted of two hot dogs, about eight Coca-Colas, a couple of O'Henry chocolate bars and some potato chips. This is what he was given every day. You cannot give somebody this every day and think he is going to get better.

#### 1050

I am now going to go into the specific areas of the legislation. There is one last point I want to bring up here. These things are all covered in our brief, which I hope you will have a chance to read. This involves forced treatment and access to the criminal justice system by psychiatric patients. We do not want civil proceedings. I have cases that have consumed three and a half or four years in examinations for discovery. We contend there is no contest between the 200 names on the left-hand side of the doctors' malpractice insurance company lawyers and our legal aid attorney. They have been in court for five years. The legal fees after two years from legal aid were \$88,000.

You could have the guy threatening anything in writing in the patient's file and it would hardly be looked at. We want these people to have access to the criminal justice system. It is very simple. They go see a justice of the peace. They say: "This guy assaulted me. He held me down. He injected me. I did not have informed consent even though I was competent." There is no certificate of incompetency in any of his medical records, in any of our cases' medical records; I have them all. If they are incompetent, certify them incompetent so that they can then have the legal framework that is in place come to them and take action. If they are not certified incompetent, they are vulnerable to intimidation, as was Mr Dockery.

The basic thing is that we want to see a strong signal sent out to these facilities that they have to provide informed written consent, they have to acknowledge the fact they cannot just drug someone and do this, they cannot hold someone down who does not want to be treated and do this, and that they should be able to go to a justice of the peace and file criminal assault charges. When we went to the justice of the peace, the justice of the peace said: "You shouldn't have gone to the psychiatric hospital. I don't see intent here. I think the doctor was really trying to help you."

This is how it works, and it is an impossibility for these people and for me. I have been there 100 times. I have 600 informations filed. Three of them had process issued. When all three got to court, all were systematically dropped by the crown attorney. In one case the defence attorney went to the crown attorney, had a little chat and a coffee. "Hi, Doris." "Hi, Mary. How are you today?" "Look, you know that thing? It's ridiculous." She went into court and said, "I'm not going to be pursuing this," without even discussing it with the plaintiff. It was just dropped.

The point is that we want to see criminal action available to these people. They are not equal. Under the Constitution they are not equal. The centre of criminology at the University of Toronto filed a report on justices of the peace, an extensive report, the first one that has ever been done, as far as I know. I have a copy of it. I am sure you could gain access to a copy of it and could go through that and see how mental patients, psychiatric patients, are discriminated against by justices of the peace. We have had them throw—I will not repeat what they have said to us, but it is like four-letter words etc: "Get out. I don't deal with mental patients."

I will now go into the aspects of the legislation we are concerned about.

**The Vice-Chair:** Just one moment, if you would not mind. You might want to be reminded that the members here might have questions to ask.

**Mr Dobson-Smith:** Oh, I did not know that. Okay, anybody have any questions?

**The Vice-Chair:** I am sorry. What I was saying was, if you would like to sum up so they can ask questions, it would be appreciated.

**Mr Dobson-Smith:** Okay. I think the most significant aspect of protection is what is actually the position. The position is that we have people walking into a subject matter in psychiatric facilities. Our group is mainly concerned with psychiatric inpatients and outpatients. This is whom we deal with. There are other vulnerable groups and there are groups that handle those. We specifically deal with these.

The point is that psychiatry is an inexact science. Five thousand studies have been done on the origins of schizophrenia. A research study on all those 5,000 studies explains that because of the broad direction taken no progress has been made. Another study on the generality of mental illness virtually confirms the same thing: "There is no rigorous knowledge of the cause, cure or even the symptoms of functional mental disorders. Such knowledge as there is, is clinical and intuitive and thus not subject to verification by scientific methods." These people are going in there, taking somebody's intuitive medication and being impeded or disabled by it for the rest of their life, becoming an actual budget drain on the health care system.

We want them to be informed before this medication is offered. We want the complete medical examination. We want full written informed consent. When these people want to lay charges of assault against someone, there is no consent form in their medical record—we find no consent forms—and they are still dropped. We want it said that it is—you know the words, I guess, to put in here—a criminal act to forcibly treat a psychiatric patient or a vulnerable person against his will without the decision-maker if he is incompetent or without the person if he is competent.

We have made provision for emergencies. We have not eliminated that. We are not talking about when a guy comes into a psychiatric hospital and is flailing his arms and needs to be restrained and things like that; we are talking about the other 95% or 99% of what happens.

With regard to psychosurgery and electroconvulsive therapy I can only say that I did the most extensive research. I had approximately 12 investigators digging up psychosurgical cases in Canada. I personally received information from the Ministry of Health in 1975 in British Columbia, from the British Columbia health insurance plan, that no psychosurgery occurred. Upon going to the BC hospital insurance, I asked the lady to give me the records on psychosurgery. They gave me the lists of the kinds of operations that were done. One hundred and fifty have been done in the last six months. Some of them were transferred back and forth from hospitals here in Toronto.

This is one very high-level researcher's summation of what psychosurgery is: "Psychosurgery is completely experimental. It has no place in any kind of treatment

methodology." He says, "The patient successfully committed suicide and the physician involved then considered the surgery a success due to the fact that this patient would never have been able to bring himself to suicide prior to the surgery." Ha, ha, ha. Terrific.

Does anyone have any questions or anything?

**Mr Poirier:** We could listen to you for days on end and you could talk to us for days on end, but I guess somebody did not tell you or remind you you had half an hour for all of us for your statement and our questions. Suffice it to say—

**Mr Dobson-Smith:** Yes, we have about seven minutes, I guess.

**Mr Poirier:** Fair enough. What you advance is extremely disturbing, very disconcerting, and I can only hope that through our work in the committee we can come out with a bill that will address these issues. I am sure that since you have been dealing with this for 20 years we have not even touched the surface of all the cases you have seen and have scientifically documented throughout your research. It is very disconcerting that things like that are still happening in 1992. This is one of the reasons I strongly support the principle, but I also want to make sure that when the bill comes out there will be no loopholes so these types of things do not happen any more, so you can be satisfied that you do not have to deal with new cases and just have to catch up with the previous cases.

**Mr Dobson-Smith:** I would love to. You know, I do not get paid for this. It takes a lot of time.

**Mr Poirier:** Being a former translator, with all that you had to say, too bad you are not paid by the word. You would have made a fortune by now. But I am glad you have gone forward. I am sure you would have a lot of background material if legal counsel or the government members want it, but we will do our best, our party anyway, to make sure we can close as many of the loopholes that are still there. I want to thank you for bringing that forward.

I have a lot of things to say to you too, but in the interest of the 5.36 minutes that are left, I will let other caucuses and other people have a chance to talk also. Thank you.

1100

**Mr Winninger:** I think a good case can be made on the basis of the evidence you have brought forward today that criminal sanctions or quasi-criminal sanctions could be beefed up to discourage the kind of violations of the safeguards under the Mental Health Act you have described. I am just wondering whether your organization or an individual has taken any civil actions for battery or false imprisonment or assault—

**Mr Dobson-Smith:** We have implemented those in the last six months. We have to, because if we cannot do anything criminally, we want some redress.

**Mr Winninger:** —or a violation of charter rights.

**Mr Dobson-Smith:** Yes. It is very hard. The other thing is legal aid. Legal aid has been wonderful to us; do not get me wrong. They have been really good. We go down and we talk to them. We explain the situation and

they just cannot believe it: "Why do we have informed consent? You know, we have informed consent. Why are you guys doing this?"

The point is that with an informed consent regulation all this stuff would stop, and not only would it protect the patient, it would protect the psychiatrist because there would be a standard level of information. A standard level of information is the only way you can actually provide everyone with equal opportunity to consent, because one doctor could have a bias towards something and another could have another bias. He can go through the written consent form with the patient, but then the patient has all the information there. His family is there. They can review it, they can think about it.

**Mr Winninger:** I infer from your comments then that you do see an important role for the advocate in assisting vulnerable patients with their legal rights, legal recourse.

**Mr Dobson-Smith:** Yes. That is another grave concern that I have. A lot of our cases did not even know there was an advocate. They did not know there was a Psychiatric Patient Advocate Office and they did not know whom they could turn to. We have had patients who have had the guy grab them and say, "If you go to the advocate you're really in trouble with us, you know," this kind of thing. They tell us this, but there are no records of any of these things.

The thing that really bothered me the most was actually the fact that it is right in the medical records that if the patient refuses, force the treatment; intramuscular injection, regardless of the fact that he is mentally competent. You people are all familiar with the fact that if a person is involuntary, it does not mean that he is mentally incompetent. I am sure you know that; the guy is still competent. He has to be certified incompetent or he has to be incompetent to consent to treatment. We feel that everyone is incompetent to consent to treatment; you would be and so would I, if I were subjecting myself to this, because I would not know that the reason I was being given this medication was addressing any problem that is causing me to have these symptoms that he is defining.

This is the whole basic crux of the matter, and a lot of the work of an advocate's office, which is obviously going to have to be beefed up with money and people on a pretty grand scale to handle all this stuff, would eliminate a lot of this unknowingness. It is hard to initially put into administration, but once it was going, they found it extremely workable in California. Suits have dropped; it is just not the same as it used to be.

**Mr Curling:** I just want to make a comment that, first, these bills are quite emotional bills and we are dealing with people's lives. Sometimes when we hear that story we are quick to move to make decisions that, I dare say, are unbalanced. We have to take into consideration that we said, "Sure we need an advocate; we have to make sure that the advocate is accountable and the person is responsible."

We do not want this government to move in and say, "We are the Big Brothers; we will take over." Everybody is vulnerable and we have to balance the doctors, the psychiatrists—all those who are involved—the advocates, the

people who are giving the consent to treatment. Therefore, as I say, we go along.

Your input here is extremely important, but in the meantime we cannot completely discredit the psychiatrists or the doctors. I know you are not saying that, so we want to emphasize that we are here, as the opposition, if you want to call us that, to remind the government that it is not the Big Brothers to do all that, but we have to make sure that balance happens. That is why I welcome your contribution.

I saw in your presentation here when you talk about the medical side of it and the psychiatric side of it that the advocates must be responsible, accountable and must be people who can carry out their duty for the betterment of mankind.

**The Chair:** On behalf of the committee, I would like to thank you for taking the time out of your busy schedules to come and appear before this committee this morning.

**Mr Dobson-Smith:** Thanks a lot. I hope you all read this.

EVELYN SCHREIBER

**The Chair:** I would like to call forward our next presenter, Evelyn Schreiber.

**Mr Poirier:** It might be a good idea that even though the people who are coming forward have been told they have half an hour, each one should be reminded by you, sir, respectfully, that they have half an hour, to take 15 minutes and also allow, at best, 15 minutes for questions. I think maybe some people are nervous, as Bob mentioned. I was not aware of that. I do not know why they are nervous with us but they are perceived to be nervous with us, and it would be greatly appreciated if you would remind each group of that.

**The Chair:** I would remind you that we are one of the gentlest committees standing right at the moment.

Good morning. As soon as you are comfortable, could you please identify yourself for the record and then proceed. We will allow you the half-hour. We would like 15 minutes for your presentation and at least 15 minutes for questions and answers.

**Ms Schreiber:** I am Evelyn Schreiber from Sault Ste Marie. I have had two children diagnosed with mental illness. One is deceased and one is in hospital at this time. I would like to ask the committee if it is all right that I have my daughter here with me for support.

**The Chair:** Of course.

**Ms Schreiber:** My son, Neil Douglas Schreiber, was diagnosed as having schizophrenia in January 1984 at the age of 16. My daughter—this daughter right here—took him to Toronto from the Sault, as he was refused admission in Sault Ste Marie. He was very psychotic, became very aggressive and hardly slept. One of his delusions was that he thought we were all plotting against him, and none of us could talk on the phone or go outside. It was almost like being held hostage.

My daughters finally were able to call the police and he was admitted to hospital. He was put on medication and seemed to respond a bit. He was released after three to four weeks and he overdosed on his medication. I had him

back in hospital again, and while he was there that time, an advocate came and told him that he had the right to refuse medication and he did not need to be in the hospital if he did not want to be.

From that time until he died, June 2, 1991, he never stayed on his medication as he should have. He would spend sometimes two months in jail in solitary confinement, and he was in hospital about 90 times for periods of one to two weeks and a few times maybe for one to two months on and off medication—very long periods without medication.

I am having a very difficult time. Please excuse me.

He stayed with me in my home from 1985 to February 1988. Due to his sporadic use of medications and his drug and alcohol abuse I could no longer have him live with me as he was verbally and physically abusive towards me. I was also taking care of his disability pension money, his living accommodation, his rent, his food, washing his clothes and cleaning his place and things like that, trying to keep him on medication at the same time and see that he got hospitalization whenever he was very ill, which was most of the time.

He would break into my home by smashing in either the doors or the windows. In his psychotic state he would come in, throw my furniture around, punch holes in my walls. It did not matter what time it was, whether it was 2 or 3 o'clock in the morning; he would come to my place and demand money, whatever he thought he needed at that time. He threatened to kill me, those kinds of things.

1110

**The Chair:** Ms Schreiber, would you appreciate it if we recessed for a minute?

**Ms Schreiber:** No, this is fine. I have to keep going. I just want to wipe my eyes so I can read.

There were many times that I had to call the police and lay assault charges against him. I would have to go to court and testify against him. He would be jailed, put in solitary confinement because he was not, as they put it, fit to be in with the other inmates due to his psychosis, his mental illness. He had been in jail at least 90 times in that period, from the onset of his illness until he died.

At times when I had to lay charges against him and, hopefully, get him the psychiatric care he needed, the Mental Health Act is so delicate that the police or family doctors would say, "Oh, we can't do that because we're afraid we'll be sued because of the way the Mental Health Act reads." He had to be a danger to me and a danger to himself. He was a danger to me many times and a danger to himself many times, as he was also very suicidal.

In one incident—there were many of them—on August 8, 1986, he was discharged from a penal institution with a one-way ticket to Toronto. Why Toronto, I do not know, because we live in Sault Ste Marie. This was on his 19th birthday. We did not know where he had gone or what had happened to him. I went to the police and reported him as a missing person. No one knew where he was.

On September 29, 1986, I had a call from a hospital in Montreal. The police had pulled him out of a river, as he had jumped off a bridge there during his psychosis or delusions,

whatever. He came back to Sault Ste Marie. Before he got back to Sault Ste Marie he had been put in jail a few times for doing bizarre things on the streets, maybe ordering food and running out of the restaurant and not paying for it or just being plain crazy.

His life and our lives were nightmares. I cannot begin to imagine his agony. Sometimes when he would be a bit stabilized on medication he would say to me: "Mom, whenever you see me getting crazy, please leave as fast as you can, because I can't stop myself and I don't want to hurt you. I don't want to kill you." He would say, "I'm afraid some day I might."

He would be evicted from living accommodations that I would find for him because when he was psychotic he would smash walls or throw his furniture around or scream at whatever was going on in his head in his delusions. He smashed his guitars.

The very last, very bad episode we had with him while he was alive was at Christmas 1990. He was very aggressive and was in and out of being psychotic. We were opening our gifts on Christmas Eve and he could not sit still. He was running back and forth and he was just very aggressive. He just said, "Give me my presents and let me go," and of course swear words, "I will da-da-da out of here and you can da-da-da do what you want." He was very verbally abusive and became physically abusive towards my daughter. She ran out the back door and he left. But about 15 to 20 minutes later he came back. I answered the door and I said, "Neil, I can't let you in unless you're going to behave." His hands were full of blood. He said, "I've come here to kill you." He tried to hit me, or he did hit me, as I ran underneath his arm to get out. I ran out on to the street, stood in the middle of the street and stopped a car. The people let me in the car after they understood what was going on, that I was in danger.

They took me to a nearby home and called the police. I watched him from there. He went into my house, into my home. The police came and took him to the hospital, because his hands were all cut up from glass, and then to jail. My Christmas tree, television, some furniture, plants, everything lay in a pile in the middle of my living room. A lot of things were smashed.

That night for some reason I went to his place after he had been put in jail. His apartment was all smashed. His new radios, Walkman, guitar, windows were all smashed and blood was splattered all over.

He was back in jail in solitary confinement again. He went to court in February and was sentenced to one day. He was sent to a hospital for 10 days before he came to court, and then back to jail and the court. He was very deteriorated by this time. His teeth were all knocked out because he had been abused on the street. His personal hygiene was not good. He was not able to even change his clothes properly or anything any more.

I tried to find him somewhere to live, someone to look after him. They said, "Oh no, he is not a danger to anyone or to himself." I said, "I believe he's a danger to himself because he's unable to care for himself. He's a danger to me. He's a danger to my family. He's a danger to anyone

he would meet on the streets because he could become psychotic anywhere."

This is just one instance. One time he went before a review committee in the mental hospital he was in and they declared him sane enough to leave. He got back to the Sault all right, but the first thing he did was, he went up to a doughnut shop and bought a cake. They said he was fit and ready to return to society; he was sane. He bought a big cake and he just pushed it in somebody's face. These are some of the things that went on in his head, and these are some of the things he would do. There are many other things.

In February I found him another place to live. The last time I saw Neil alive was three days before I found him dead. On June 2 I went to visit Neil as I did three to four times a week. I had misplaced the key to his apartment. He did not answer the door, so I thought he must be out for a walk or maybe visiting someone. That is what I wanted to believe, because he did not answer when I knocked. It was a nice sunny day. So I went back home.

I went back again the next morning, Monday, about 11 o'clock. I knew he was dead. I tried to get in touch with his landlord to get a key to let me in, but the landlord said he did not have time to go home to get his key and all this kind of thing. So I phoned the police—they were well aware of Neil; they all knew Neil—and told them I was sure he was dead because of what I could smell coming out of his apartment. They said they would go right away and attend to it. I just told them: "I'm sorry. I can't go with you." They said it was all right. I asked them to call me back right away, regardless of what they found. They called back and told me Neil was dead.

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**The Chair:** In the few remaining moments, maybe what you could do is offer some suggestions on how we could avoid this happening again.

**Ms Schreiber:** The way the Mental Health Act reads, there are no places for people like Neil. Anywhere I have gone or any time I have spoken to an advocate, they have been anti-medication, "He'll be better off without," but they do not know my family members who were ill or what they were like before they became ill. They were kind and loving. Can I just say a little bit about my daughter here, please?

My daughter Sandra was diagnosed in 1985. Her life went very much the same as Neil's, very much the same up until now. She was very suicidal. She had, I do not know, maybe 14 suicide attempts but lived on the street because she was not able to live with me. She became pregnant and gave birth to a child four years ago and she lived on the streets until the child was born. I had to talk with the children's aid, social workers, whomever, to make sure her baby was not born on the street. The baby was born in the hospital, made a ward of the children's aid, and is, as far as I know, adopted out.

I hope and pray to God that it is a warm, loving, caring home because we read so many things today about child abuse, especially with adoptive parents or care givers, and this not knowing breaks my heart. I have never been able to hold this grandchild or even see this grandchild or

acknowledge this grandchild. She talks today of her child, and two days after her baby was born she was back living on the streets. Somebody I know saw her sleeping in a doorway. She had been in and out of jails very much the same as Neil.

I feel that both my children have fallen through the cracks because of the way the law has been a barrier to treatment for them. The advocates have no real knowledge of their illness or what they were like before. They only see them just a little bit while they are in the hospital. There is no ongoing care given to them from any advocate that I am aware of, other than saying to Sandra or Neil, "You don't need to be in a hospital. You don't have to have this medication if you don't want to."

I realize the side-effects of the medication, but either they are crazy or a little bit stabilized by this medication. It is catch-22. That is how I see it. I believe that the parents or the family members who know the mentally ill person should have some say or should be able to give some information or input into the treatment of this mentally ill adult or child.

There is very much abuse of drugs and alcohol along with this. My daughter never drank or smoked before she became ill. Now she drinks and she smokes and she abuses drugs as well.

**The Chair:** Thank you. If you would not mind a few comments and questions?

**Ms Schreiber:** I will try to answer them.

**Mr Poirier:** Could you elaborate a bit on who these advocates were you consulted who would tell your child, Neil, that he did not need to take his medication and what-ever?

**Ms Schreiber:** Lawyer.

**Mr Poirier:** Lawyers?

**Ms Schreiber:** One. A lawyer, yes. A lawyer and people from advocacy groups. I do not know their names.

**Mr Poirier:** Were these people you sought out to consult or who were appointed to help you by somebody? How did it come about?

**Ms Schreiber:** They were appointed to help my ill daughter and son.

**Mr Poirier:** Who appointed these advocates?

**Ms Schreiber:** By the law, to tell them their human rights from the courts, I believe, according to the Mental Health Act.

**Mr Poirier:** If I understand what you have said, you do not perceive that experience to have been very—what word could I use—positive. You did not appreciate the type of advice they may have given your son and daughter. Did I read you right?

**Ms Schreiber:** Yes. It did not seem to do anything, to get them the help they needed. It discouraged them, because in their psychotic state of mind they are unable to distinguish one from the other. If somebody told them one thing and somebody told them the other thing, then they were just totally confused. But one thing, they did not want to be on medication. They refused medication.

**Mr Poirier:** Did you feel that these advocates did consult you or take into account what you had to say or think?

**Ms Schreiber:** I did have a meeting with one. I just met him in the hall of the hospital. He came up to me and said, "You know, your son, Neil, doesn't have to be here. He shouldn't be here." I looked at him and I just said, "Yes, he does need to be here. That's why he's here." He said, "You can just take him home today if you want." I said, "No, I worked hard to get him in here because of his mental illness. He is a danger to himself and to others because he would one minute just be sitting quietly and then all of a sudden this rage or craziness would go on in his head and he would attack. You never knew what he was going to do."

**Mr Poirier:** Okay. Thank you for coming forward and sharing that with us. I have many more questions, but take it away, Mr Chair.

**Mr J. Wilson:** Thank you, Mrs Schreiber, for having the courage to give us your testimony today.

Along the same line as Mr Poirier, I assume you have made many attempts over the years to try to get people to listen to your side of the story and how your children were at home. I am particularly interested in, when your son was taken to the hospital on the one instance with blood on his hands, how the police could not interpret that as being a danger to himself or others.

**Ms Schreiber:** They did at that time.

**Mr J. Wilson:** They did?

**Ms Schreiber:** At that one time, yes.

**Mr J. Wilson:** You mentioned he was given 10 days of assessment prior to the court.

**Ms Schreiber:** Yes. I went to the court and to his bail hearing or whatever it was, and I heard the doctor there testify that Neil should have a 30-day assessment. But it was only a 10-day assessment because he was right back in the Sault Ste Marie jail in about 10 days. It certainly was not 30 days.

1130

**Mr J. Wilson:** Did the judge not request any further treatment for Neil?

**Ms Schreiber:** The doctor in the psychiatric hospital made a strong recommendation that Neil be put on a Lieutenant Governor's warrant at that time.

**Mr J. Wilson:** That was not followed up by the court?

**Ms Schreiber:** No. He was sentenced to one day with nowhere to go.

**Mr J. Wilson:** Just so you will know, and I am sure you do know, your plea to us to try to ensure that in the new legislation family members and those who are trying to do what is best for their loved ones have some say in getting their loved ones into treatment and that sort of thing is something we have heard consistently. The problem the government runs into is that in our society, as you know, under the Charter of Rights and Freedoms the individual has significant rights that, according to the Constitution, have to be safeguarded.

I do not know if we are going to come up with the balance you require, that the family have some input. If we cannot get it into the law, we will have to get it into the training of advocates to ensure they take a balanced approach to not only informing the patient of his or her rights but also ensuring that the family's wishes and experience are taken into consideration, because you are the person most experienced in these cases.

**Ms Schreiber:** Yes, because I have never had any help from an advocate coming forward and saying, "I'll help you find a place."

**Mr J. Wilson:** It is almost as if families need advocates too.

**Ms Schreiber:** That is right. We need to be heard and to have some say. We need help dealing with our mentally ill son or daughter. I know of many families that have also—

**Mr J. Wilson:** Including my own. So you will know, I have a brother with schizophrenia, and while it has not been as tragic as your life, it very much parallels the weekly incidents that families put up with, and when the system throws your brother or child back to the family, ignores you, but then expects you to look after the child too, it is very frustrating.

**Ms Schreiber:** It is not only frustrating but it is very fearful. It is like I am powerless. There is nowhere to turn. There is no help. We do not have anything to protect us. I had to change jobs because I was not getting the rest to do the proper job I was doing because for years I hardly slept or I had to leave and sleep somewhere else. There are many other families that belong to the Ontario Friends of Schizophrenics chapter and they all have the same horror stories, pretty much the same as mine; most do. Some of them have even been held hostage by their ill child, much the same as Neil would do to us at times.

**Mr Winninger:** You, like many family members, have come to the committee and expressed the frustration felt in trying to get treatment for children or spouses. Under the Mental Health Act, of course, the psychiatrist would have to find the patient incompetent to consent to treatment at the time of examination. This has led to problems where people need treatment but are not aware of it. In fact, many times they check out of hospital whether they are getting treatment or not.

Our legislation, Bill 108, the Substitute Decisions Act, in combination with Bill 109, the Consent to Treatment Act, should actually afford parents and other family members more assurance than they had before because you can apply as a family member and, as a family member, you would probably be preferred to become a guardian for the personal care of that child or other family member. By being appointed guardian, and if the order so provides, you can actually have that family member admitted to a mental facility and presumed to be admitted voluntarily.

Moreover, as a guardian of that person you can consent to the treatment of that person, and again it is deemed to be voluntary because you have been judicially appointed as the guardian for that person. As has been pointed out in several other cases, this helps with the revolving-door syndrome where family members check in and out of facilities; get

treatment for a short time and then go off it. This will ensure that you as a family member can demand and receive the kind of treatment for your cherished family member that you want. I think it is important that the public understands the impact of this.

**Ms Schreiber:** That sounds very good, but what bothers me or confuses me is, I will be the guardian and I have to care for or look after whatever my child is doing 24 hours of the day, 365 days of the year. What happens when I am sick—I have been in hospital for different things—or I have to go away somewhere, like I am here now?

**Mr Winninger:** That is where you need the support services.

**Ms Schreiber:** Who would be there to be the guardian when I am not there?

**Mr Winninger:** I suppose you might have different scenarios. You might have partial guardianship where your guardianship would just extend to giving consent. You have mentioned the hospital and treatment, but you make a good point; you do need those support services. Virtually every guardian probably requires support services in the community to do her or his job.

**Ms Schreiber:** Also, what happens when Sandra, my daughter—we will use Sandra as a for-instance—decides to jump in somebody's car and ends up in Vancouver? She did end up in Vancouver where no one knows her and she got put in jail. That has happened to her; she just got put in jail and was back out on the street, that kind of thing. That is something else that I do not see working, this guardianship.

**Ms Carter:** We certainly feel for you, and you made it very clear that something here needs to be addressed. I am not sure whether the advocates you speak about work for the advocates under the Psychiatric Patient Advocate Office, but I just want to make it clear that as a body it is not opposed to medication and would not advise somebody to refuse it. Its function is to give information to the person regarding his rights and his rights of appeal, to determine his competency and not to oppose medication as such, although we have heard presentations here—we had one this morning—from groups who are opposed to medication as such, so I wanted to make that distinction.

**Ms Schreiber:** I do not suppose they are totally opposed, but they say this to someone who is ill, a mentally ill person who does not want the medications in the first place because they think, "You're trying to poison me; you're after me," in those states of being crazy.

**Ms Carter:** It is a question of whether the person is in a state to make that decision, is it not?

**Ms Schreiber:** Yes. In one instance that happened, my daughter was in the hospital and an advocate came in to tell her her rights, so then she went around and told all the other patients their rights and they all refused medication. It caused a lot of chaos on this floor.

**The Chair:** Mr Wilson, one brief comment.

**Mr J. Wilson:** I just need a quick clarification, Mr Chairman. The comments by Mr Winninger I do not think should stand alone. I would like clarification from the parliamentary assistant. I think Mr Winninger is correct to a

point, except that under Bill 108, if the patient appears to have a lucid moment when you finally get that patient, say, to the emergency ward, the doctor says, "The patient does not seem incompetent to me," and the patient therefore could then refuse treatment. We had testimony yesterday where indeed that was the case. Is that not the case? Are not the most recent wishes of the patient to be honoured?

**Mr Winninger:** We may get a further opinion as well, but I think it should be clear that this is not like an enduring power of attorney where the patient can express a more recent wish that might run contrary to the earlier desires expressed in the power of attorney. We are dealing with a judicially appointed guardian here, and I do not think the attending physician can ignore the wishes of the judicially appointed guardian.

1140

**Ms Bentivegna:** The Consent to Treatment Act states that if there is a guardian acting then there is no determination of capacity done at that time, and it is the guardian who acts for that person. The only way would be to go back and revoke the guardianship order.

**Mr J. Wilson:** And the courts, in giving the guardianship order, we would expect, would give a time frame for that guardianship?

**Ms Bentivegna:** It would be open to them.

**Mr J. Wilson:** Okay, thank you.

**Mrs Cunningham:** My question is—I cannot see the part here in the act itself—to appoint the guardian in the first place, you have to declare that the person is incapable of managing his own affairs, is that not correct?

**Mr Winninger:** It depends whether you are talking about guardian of a property or guardian of a person. When you talk about—

**Mrs Cunningham:** I am talking about a person.

**Mr Winninger:** There has to be a finding of incapacity.

**Mrs Cunningham:** That is right, and I would suggest that in many of the cases that some of us are involved in in our offices, because we meet with the parents of some of these young people, they never would get guardianship for that purpose because it would be very difficult even to prove your son or daughter incapable on an ongoing basis.

**Mr Winninger:** We have heard a number of presenters giving anecdotal evidence about their family members who went out in the bitterly cold weather with no coat on and other examples like that where clearly they cannot make decisions that would indicate capacity. In these kinds of situations an appointment of a guardian would be warranted, and I think a court would find it warranted.

**The Chair:** Ms Schreiber, on behalf of the committee I would like to thank you and your daughter for coming and giving such a personal presentation.

**Ms Schreiber:** Thank you for allowing me.

**Mrs Cunningham:** Mr Chairman, could I just ask a question through you to Mr Winninger, because I think this is an important point. I do not think that this particular legislation would change the method by which the law right now can appoint someone as a guardian. Am I correct

on that? We have a separate piece of legislation right now where people are declared before the courts to be incapable of managing their rights. That exists at this point in time; that is my understanding. I just want a clarification on that.

**Mr Winner:** Under the Mental Incompetency Act there is a provision to appoint a guardian of the person, but it has virtually never been done.

**Mrs Cunningham:** So we have existing legislation now which we can apply, but it is just not used, is that your point?

**Mr Winner:** Not as it stands. Mr Fram certainly is the expert in this area.

**Mr Fram:** One of the difficulties with the Mental Incompetency Act is that it has many provisions addressing the issue of management of property. It has one provision that says, "By the way, you can also be the committee of the person." It does not say what powers a committee of the person has. It does not say what limitations apply. It was designed in the 19th century when treatment was not much of an issue at all, so it does not address all of the issues that have taken place with respect to treatment and care in the 20th century.

**Mr Chiarelli:** In what circumstances under Ontario law can somebody apply to be appointed the committee of the person, other than the Mental Incompetency Act?

**Mr Fram:** There is no other provision.

**Mr Chiarelli:** Did I understand somebody to say that it is very unusual and that it is not done?

**Mr Fram:** There may be a few exceptions, but it usually arises out of hospital care. Under the Public Hospitals Act there is a regulation that provides that the public trustee can apply for committeehip for the purpose of making an order about treatment of a patient with nobody else to make decisions for him when the person is in a public hospital. The public trustee's office has been doing that for the last year or so.

That, basically, is all the use that is made of it. It used to be used in the past sometimes when hospitals would get a clergyman, the pastor at the hospital, to apply for the guardianship or committeehip of someone who did not have any family to make a decision for him. That is the use of the Mental Incompetency Act today. By and large, because it does not say what authority a guardian or a committee of the person has, nobody knows what the limits are, the authority to the review the—it is just sort of an add-on to the authority to manage property.

**Mrs Cunningham:** I think it is a very important point, if you do not mind, Mr Chairman. On section 46 of Bill 108, where they are describing that the person is incapable of personal care if the person is not able to understand information, and it goes on, is that the part of this bill that would describe an incapable person?

**Mr Fram:** Yes.

**Mrs Cunningham:** Who decides that the person is incapable?

**Mr Fram:** The process the bill provides is that, first, there is an assessment of capacity by assessors of capacity—that is, people who have training in doing assessments. If the

application is uncontested, then the documents are filed, along with a guardianship plan—that is a plan saying how you plan to use the power—with the public guardian and trustee's office. Then, if there is no dispute, no appearances filed, an advocate goes out and sees the person who may have a guardianship imposed. If no objection is filed to the guardianship order, it will go before the court with no hearing, and unless the court is concerned, an order will be made. If the matter is opposed, if an appearance is filed in court, then the matter will be decided by the judge.

**Mrs Cunningham:** Does that exist right now, or is that because of this new law?

**Mr Fram:** That is because of the bill.

#### PEOPLE FIRST OF ONTARIO

**The Chair:** I would like to call forward our next presenters, from People First of Ontario. Good morning. As soon as you are comfortable, could you please identify yourselves for the record and then proceed.

**Mr Sears:** My name is Norval Sears, president of People First of Ontario. On my right is Patrick Worth, past president of People First of Ontario, and on my left is Judith McGill, our provincial adviser. The reason we have an adviser here is to help us understand a lot of things that we do not understand when we are having trouble understanding, and she is also here to help us to get through our presentation if we get stuck or something.

Just a little bit about us: Our group has all been labelled. We have a board, which is all labelled, so it is not run by outsiders or advisers or anything. We run our own organization. We also have advocacy as part of our organization, and so on down the line.

I have two stories to do with the advocacy part. One is what would happen without an advocate, and the other one is with an advocate involved.

The one without an advocate: We had two members, Tom and Linda Moore. They did not have an advocate in place at the time they had their children taken away from them by the children's aid society. Before that, they told their stories to the police. At this point, Linda Moore was raped, so they went to the police to tell their side of the story. What happened was they separated Linda and Tom. Instead of bringing them together and letting them both talk about her story, they kept them separately. Linda told them she had been raped. They did not believe the story at all at this point. Then when it got to the court system, she told her story again, but no one at the court believed that she has been raped. They think she is making the story up.

What happened was, down the road, their children were taken away from them by children's aid because they could not look after them. They came up with some kind of excuse, saying something about their not treating their kids right.

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Down the road, we advocated on their behalf at one point. We also had some help by lawyers to put it in perspective and help them with the legal system. Unfortunately the legal system did not help them at all. At first it started helping them pretty well, until one person did not think they had any other chance, so she stepped down from the position.

The final thing was the legal system took over, actually, at that point. What happened was, their children were taken away from them. They tried to fight to get them back but did not succeed. They have children's aid involvement. They have been seeing them once a week, with a person there with them when they see their children. Their children could not call them mom and dad at all, because they did not know what their mom and dad looked like. So they could not call them mom and dad at that time.

Anyway, down the road there was not much offered, so they had them consent to a form to legally have somebody adopt their children. At this point the husband could not read or write. Whatever was in front of him, without an advocate there to help, he signed that paper without realizing what he had done. The adoption was done legally. In other words, he gave up his own children with this paper. That was part of the story of what can happen without an advocate there.

The other story is partly my story. I had an advocate helping me through my life at one point. I had a lot of pressure built up in me. My son was born a little earlier than he was supposed to be. I had a lot of other commitments brought into my life right then, such as how to support my wife and my child. But a lot of people said I could not get married or have a child at all. A person I know who is very trustworthy and close to my heart said I could do anything I wanted to do, because you have to believe in yourself. You can really work your hardest if you believe in yourself. What happened is, we talked a lot about my troubles and we worked it out together. He said to me, "Just take one day at a time; you start with one thing and then you finish what you have to do."

I have done that and it has turned out pretty good, because this person really gave me a lot of advice. I still go to him once in a while to talk about the other pressures I have. We work it out together. It worked out fine for me, because now I still have my own son, whom I almost lost in a way to the children's aid. I am married and I do have a son and he is still with me right now. This person really helped me out wonderfully. Without an advocate I probably would have folded and gone underneath the pressure which built up, and I probably would be broken down or in a hospital or something.

Advocacy is the most important thing right now, and there is a case we are dealing with, the Christopher Robin inquest, with these kids. These kids did not have an advocate who could speak on their behalf. I know they were just infants or one-year-olds, but still, they did not have any advocate to tell the doctors not to give them what they gave them. They can let them die. If they had an advocate, I would think they would have a better life than what they have right now. Most of them are dead now.

So I think this advocacy is really important to all of us who have been labelled, because we are people who have been labelled as having trouble with everything. We like to live out in the community, and most of us do, but it is just that label that is bringing us back. If there was an advocate in place, the lives of these people who are in institutions would probably be a little different from what they are right now. So this advocacy part is really important.

I would like to just turn the rest of it over to Patrick Worth.

**Mr Worth:** Just a brief background of the advocacy review. Back in 1986 when the government decided to appoint Sean O'Sullivan to put together a review, he decided to do this by getting together a consumer advisory committee which was made up of people with disabilities representing their organizations. I was the member from People First of Ontario sitting on that committee.

I spoke to Sean O'Sullivan about the lifetime that People First members have had of being isolated and institutionalized. He took to heart what I had said about my own personal experiences and those of the other people who have had personal experience of segregation and long-term institutionalization. He began to realize that there needed to be a shared advocacy model of paid advocates as well as volunteer advocates. We are people who have had a lifetime of just paid people in our lives and it has led to nothing but big bureaucracy and segregation and people having control over our lives. We do not believe it has to be that way. We have to have the power, as decision-makers, to decide who our advocates are and what role they will play in our lives.

Sean O'Sullivan called the review a shared advocacy model because he did take to heart what he heard from People First members about how vulnerable people are when you have just one system for one group of people that segregates them and labels them as mentally handicapped. The title is *You've Got a Friend* because O'Sullivan really believed that advocacy should mean you have a friend—not a bureaucrat, not somebody representing a service, not someone paid to represent a service or advocating for a service but somebody advocating for needs of people who are vulnerable and answering to those people.

The independent advocacy system must be consumer-controlled. We must have a commission of people with disabilities that is majority-run by people who have suffered in isolation, institutionalization and segregation and who know what it is all about to teach advocates how to advocate for vulnerable people, to teach advocates to feel the sensitivity and the personal feeling of friendship and to know that we must have friendship and advocacy.

It must not be allowed to become another bureaucracy. We must not have another bureaucracy that fails people, that becomes so bureaucratic we just deal with things on a business level, file things away on people, keep records of people for our own statistics and people just become a statistic.

1200

The independent advocacy system must be easy to access. People have to know how to get in touch with people and to know who their advocates are. Most important of all, it must be very personal. We have suffered too much with people who have not felt the same things we have felt about punishments we have had in segregation and isolation, both in institutions and isolated communities. We must have a personal feeling towards each other and it must be an equal relationship between the advocate and the individual.

At the People First of Canada founding convention this year, our membership voted in favour of taking a stand

against guardianship legislation. We must not have a law that takes away all the rights of an individual. Whether or not people can speak for themselves should never be an issue. People should have the right to exercise a right. People should always have the right to an advocate. People should always have the same rights as people who can speak for themselves. I very often think that what is needed is for people in society to truly listen to people whether or not they can speak for themselves.

We call ourselves the decision-makers for people who are vulnerable but we should not be, because empowering people means that you respect the right of people to make their own decisions. You help them make their own decisions; you do not decide that they cannot make their own decisions. You must decide to support people in coming to a decision in an equal relationship.

The issue of the adult protective service workers becoming advocates under the independent advocacy system needs to be reviewed. APSWs do case management work; that is a program. I do not know if it is clear to all APSWs that if they become advocates under the independent advocacy system they cannot run a program; they must be there for the personal needs of the individuals.

We think we must have the right to decide who our advocates will be. That is the importance of having an independent advocacy system controlled by people who are vulnerable. We will remain vulnerable if we cannot have the right to decide who our advocates will be. If we have guardianship legislation you take away all of our rights. By law, you take away all of our rights and it becomes the right of another person to decide what to do with another individual's life.

**Mr Chiarelli:** I want to thank you both very much. I think you have explained very graphically the issues we are dealing with and, without saying so, you have demonstrated that it is a very difficult area to legislate in because we are dealing with people's feelings, we are dealing with their emotions and we are dealing with their dignity, and it is very difficult to legislate that type of issue and pass laws on that type of issue.

I think what you are saying, and I would like you to explain it to me, is that if there is a good system of advocacy for certain people, a partnership between the advocate and the individual will eliminate the need for guardianship. Is that what you are saying? If there is a good marriage between the advocate and the individual, then you do not need that label of guardianship or the legal umbrella or framework of guardianship.

**Mr Worth:** That is partly what I am saying, but I think we are also saying that guardianship does the opposite. It eliminates the friendship that people could have, the more personal friendship, because if you have the right to decide by law and make all the decisions in a person's life, you will always have more social status than the vulnerable individual.

**Mr Chiarelli:** Obviously there are different levels of decision-making which apply to different levels of vulnerability, if I can put it that way, in terms of an individual. Even the word "vulnerable" is a label in itself. There has to

be collective decision-making in certain circumstances at any level of decision-making. I like to share and get the advice of my wife on major decisions that affect me. On political decisions I like to have the advice of my colleagues. So there has to be some partnership in decision-making, but there is a range of experience and capability. If I am going into something new, different or difficult in the political arena I will put a lot more weight on some of the advice I receive from people with experience. Obviously there will be certain circumstances of some individuals who have much less experience and knowledge in decision-making. How do you decide the role of the advocate or, if this legislation were to proceed, how do you decide the role of the guardian in making that collective decision?

**Mr Worth:** Let me take a shot at it. It is a difficult question but a necessary one. What makes it collective is an equal partnership. There have to be collective decisions made, but if it involves that individual's life it must be a decision made to respect that individual's decision. If the individual disagrees with you, then a collective decision must be made to respect that decision.

For instance, Judith McGill is our adviser, but she often acts as our advocate too and she is our friend. She gives us advice and she talks to us about personal things, but she always allows us to make our final decisions. It is sort of collective because we do go to her. We do not make decisions without talking to her and without respecting her point of view, because she has become a personal friend. That is why the relationship has worked, because we feel the sensitivity of how vulnerable people are.

**Mr Chiarelli:** Some people who have been before this committee have suggested that the advocacy part of this legislation should proceed but that the other aspects of it such as guardianship, consent to treatment etc should be deferred for further discussion or refinement. Do you agree that from your perspective the advocacy portion should go ahead but the guardianship part of it should not go ahead?

**Mr Worth:** I think you have to look at the advocacy legislation carefully. We believe that persons who cannot speak for themselves should have the right to an advocate as much as the person who can. That is not clearly identified in the advocacy legislation and we want that to be clearly identified in the legislation before it goes ahead.

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**Mr Chiarelli:** You want to see the act changed, then, even the Advocacy Act?

**Mr Worth:** There are some changes that need to be made. The guardianship legislation: It is our sincere hope that you would decide to drop it, because it does not empower people.

**Mr J. Wilson:** Thank you very much for your presentation. You bring up a very good point about guardianship.

My question, in my own attempt to understand fully what it means, is to the government, through you, Mr Chairman. When someone goes to court for a full guardianship over an individual, my understanding is that you would have to ask the court for specific elements of that guardianship. For instance, say I were to go to court for guardianship, I would ask the court to specify in the court order

that I would be able to make decisions with respect to treatment and with respect to admitting that person to a psychiatric facility. Can I only ask for those elements in which the court deems that person to be incapable? Because we also know that a person can be capable and incapable with respect to certain treatments.

**Mr Fram:** The court can only give a guardian power over those areas in which the person is incapable. That is, unless it is established that you are incapable with respect to those kinds of decisions, the court cannot grant you the authority.

**Mr J. Wilson:** I understand that. I will talk to you separately to get a feel of what actually would go on in court in deciding what areas one would be capable in and incapable in.

**Mr Malkowski:** Thank you for a wonderful presentation this morning. I have been out to meet some of the People First, and I think it is a marvellous organization. I think it is wonderful to see how they demonstrate they can run their own meetings. I was so impressed when they had me to their meeting. When I have been there and been able to observe some of these people in action, they run their organization just like everyone else, and it is great to see that.

Now, related to the Advocacy Act, do you feel that the Advocacy Act is necessary then as a foundation to get through? Would you like to see that move ahead? Do you agree with that?

**Ms McGill:** Could you repeat that last part so that Norval could hear it, please?

**Mr Malkowski:** What I am wondering is, would you like the Advocacy Act to move ahead, to proceed, to be passed? Would you think that would empower and help people?

**Mr Worth:** We would like to see it move ahead, but we think that it would be a mistake to exclude people who cannot speak for themselves from the act. We would like to see it move ahead with those recommended changes in the act.

**Mr Malkowski:** Do you have any specific recommendations, things you would like to see in it?

**Mr Worth:** It must be a sure advocacy model. It must be both paid and volunteer.

**Ms Carter:** I just have one question to ask you. The advocate as described in the act is somebody who listens to the client and expresses his wishes and desires. You are saying that advocacy should be extended even to those people who cannot express their own wishes, and I am not quite sure how that is possible. If the advocate cannot ascertain what that person's wishes are, how can he function?

**Mr Worth:** Well, we think they can, if you stop thinking in terms of people as clients. That leads to a more impersonal relationship, and people cannot possibly understand under those circumstances. But we feel, and we have seen it happen, where vulnerable people who come out of institutions, people have made homes for them, not because they can understand every word, but because they can understand the feeling of a more personal relationship.

**Ms Carter:** I see. You are saying that because the relationship is a more informal, intimate one, a much larger range of people can be included because their wishes will become clear in that kind of relationship?

**Mr Worth:** Yes.

**Ms Carter:** I see.

**Mr Winninger:** Just briefly, I wonder if you would agree that there are some people in society who may be totally incapable of making decisions. I am thinking, for example, of an extreme case of someone who is in a coma. Do you think that would be an appropriate situation calling for guardianship?

**Mr Worth:** No. I think that calls more for the most important reason why an advocate must be a friend. I think it calls for the most important reason that, even though somebody is sleeping or somebody is unconscious and cannot hear you, he can feel your presence.

**Mr Winninger:** Would it concern you if people who were not guardians were making the kind of decisions that guardians make but not being accountable to anyone—not to a court, not to a board or not to any authority? Let's take your example of an advocate as a friend. Would it concern you if that advocate were making decisions for someone who could not make decisions, and yet would not have to account to anybody?

**Mr Worth:** Accountability must be always to the individual. We are talking about declaring somebody mentally incompetent by law. Who do we always say the law is supposed to be there to serve? If we declare people mentally incompetent we are singling people out, and when people are singled out they always become vulnerable. They are mostly segregated and mostly poor. That leads to a big bureaucracy and that leads to service providers and that leads to a number of ways that people can be potentially exploited. But the most crucial point about being labelled mentally incompetent is that we already have so many labels. We do not need another label.

**Ms McGill:** Just for clarification. David was asking you whether or not advocates should be accountable to a legal system or to some other kind of system, and you are saying that the accountability should always be to the individual?

**Mr Worth:** Yes.

**Ms McGill:** And that is part of your partnership model: If they had a sense of the person they would always go back to what they feel the person would want and need.

**Mr Worth:** Yes. That is why Sean O'Sullivan titled the review of a shared advocacy model *You've Got a Friend*.

**Mr Winninger:** I think I understood what he was saying. I may not agree with it, but I think I understood what he was saying.

**The Chair:** Thank you, Mr Winninger. Mr Worth, Mr Sears and Ms McGill, on behalf of this committee I would like to thank you for taking the time out this morning and giving us your presentation. Thank you. This committee stands recessed until 1:30 this afternoon.

The committee recessed at 1219.

## AFTERNOON SITTING

The committee resumed at 1341.

**The Chair:** I would like to call this meeting back to order and call forward our first presenters, from the Easter Seal Society.

**Mr Chiarelli:** Mr Chairman, I wonder if I could make a brief motion before that.

**The Chair:** Yes, Mr Chiarelli.

Mr Chiarelli moves that the standing committee on administration of justice sit for an additional two days, or so long as is necessary, to accommodate the list of people who have asked to present briefs to the committee.

**Mr Wessenger:** I am just wondering, Mr Chairman, is it possible to have this referred to the subcommittee for discussion?

**Mr Chiarelli:** No, I would prefer not to, because we had a subcommittee meeting yesterday where we agreed to do just that, and we came in and presented the subcommittee meeting and the government side asked for a recess and came in and voted it down. I think the discussion should be on the public record that the committee has before it a request by somewhere between 10 and 12 presenters, including the official guardian, and that we have an obligation, I think, as MPPs, to accommodate the people who want to make presentations. I think that should be on the record.

**The Chair:** Any further discussion to Mr Chiarelli's motion?

**Mr J. Wilson:** I would support the motion in light of the fact that some very well-informed groups would like the opportunity to present to this committee, including, I believe, the public trustee of the province. I think it would be very important to have that input before final legislation is proposed to the House.

**The Chair:** Further debate, Mr Malkowski?

**Mr Wessenger:** Mr Chair, I would like to have some information—

**Mr Malkowski:** I would like to ask for a 10-minute recess, please.

**The Chair:** There is no vote being called yet, but if you want, we can call a 10-minute recess.

**Mr Malkowski:** Yes, I would like to do that, please.

**Mr J. Wilson:** Do we get to vote on these recesses?

**The Chair:** This committee stands recessed until 1:55.

The committee recessed at 1343.

1351

**The Chair:** I call this meeting back to order. Further debate on Mr Chiarelli's motion?

**Mr Morrow:** If it so pleases the committee, I would like to add an amendment to Mr Chiarelli's motion. I would like to delete "or so long as is necessary" and put two specific days, being March 24 and 25.

**The Chair:** The committee cannot determine which days we sit, that is up to the House leaders and the whips,

but you can have the amendment to delete "or so long as is necessary."

**Mr Morrow:** With the two specific days. Thank you very much.

**The Chair:** Debate on the amendment? Seeing no debate on the amendment, all those in favour of the amendment? Opposed?

Motion agreed to.

**The Chair:** Further debate on the main motion, as amended? Seeing no debate on the motion, as amended, all those in favour? Opposed?

Motion agreed to.

**The Chair:** We will now refer this to the House leaders and the whip's offices to determine whether or not we can sit for the extra two days.

## EASTER SEAL SOCIETY

**The Chair:** I would like to call forward our next presenters, from the Easter Seal Society. Our apologies for the delay. As soon as you are comfortable, would you please identify yourself for the record and then proceed.

**Mr Dawson:** Thank you for giving me this opportunity to speak to you on behalf of the Easter Seal Society. My name is Alan Dawson. As well as being a representative of the Easter Seal Society, I am also the parent of a child with a disability. My daughter has spina bifida, hydrocephalus and uses a wheelchair. She is nine years old now. Just over a year ago, when she was seven, she had a major brain haemorrhage which further impacted on her disability: She lost the use of her right arm. But she maintains a positive and very active outlook on life and nothing has changed in her personality.

The Easter Seal Society celebrates its 70th year as a charitable provincial non-profit organization. We are dedicated to helping children with disabilities achieve their full potential and future independence by providing direct services, program research, advocacy and public education. Programs I am sure you are familiar with are nursing services, camping, preschools for disabled children, financial assistance towards the provision of equipment and parent support services.

As of September 1991, there were 7,904 children on the case load in Ontario, 7,158 of whom are children under the age of 16. The society has 3,640 moderately dependent children on the case load and 1,759 totally dependent children. These are children who need the support of family or some medical services to maintain their existence. Of these children, 1,766 are non-speaking as well as being dependent, and 268 are medically fragile and technologically dependent; 20% of the children come from one-parent, female-led families existing on a single income; 38% of Easter Seal families earn below \$20,800 per annum, with 14% earning less than \$9,000 per annum.

We are astounded and extremely disappointed that in a country where human rights are treated with the utmost respect an act could be proposed which excludes the most

vulnerable group of our society. I am referring to Bill 74. I cannot help wondering what the rationale is for excluding these children who are every bit as vulnerable as any adult. Is it perhaps expected that parents will adopt that advocacy role? This presumes that parents are endowed with the necessary skills, experience, confidence and knowledge to articulate for their child's individual requirements or, on a grander scale, for systemic changes.

Parents of a child with a disability are subjected to a variety of additional stresses other than those associated with normal parenting. As a parent, I can attest to this fact. There is an initial process of grieving when you first find out about the child's disability or when the child is born, tremendous guilt feelings and a variety of emotions as parents learn how to deal with one crisis after another. It is a never-ending cycle; it never stops.

Many medical procedures which are normally carried out in hospital are performed by parents at home. These can include physiotherapy and catheterization. Catheterization is something that is done on an intermittent basis. It is done in schools by teachers' aides; it is done at home. The families have to provide that service. Physiotherapy is the same thing. You have physiotherapy but you have to do some of it at home.

Where other children are involved parents must meet their needs as well as earn a living. Financial problems abound, as special equipment such as wheelchairs, vans, lifts, home renovations, private therapy—many children need therapy on a frequent basis; they cannot access it through the system so they have to resort to private therapy; most families cannot afford it at \$60 an hour—have to be paid for.

Families are often forced into heavy debt as the only option of preserving their child's wellbeing and independence. Most of us as parents are trying to maintain as much independence for our children to make those who are able to get out to work earn their own livings. A lot of them are going to do it but they need a lot of help. Many mothers cannot make the choice to work to help the family finances, so it automatically means most families are a one-person-income family.

The physical demands on individuals cannot be imagined. You can imagine that some of these children get kind of heavy. You have to lift them into baths; you have to lift them in and out of bed. It is not easy. The constant strain of having to give them their treatments at the appointed times, getting them in and out of cars, getting them in and out of vans, is a tremendous physical strain on families.

Stress is often transferred to the marriage, resulting in many breakdowns. This places further stress on families and breaks even the most resilient human will. Many families rarely if ever get out as a family and many husbands and wives rarely do, even for anniversaries or birthdays. They cannot afford to, they cannot leave their child because you normally cannot leave a child with a disability with a regular babysitter, or they are simply too fatigued; they are too tired. How can they then be expected to have either the time or the energy to advocate? Certainly not efficiently, especially where systemic advocacy is required.

1400

The load for a parent with a disabled child is heavy indeed. We need help. We need your help and we need the help that can be provided by Bill 74. If the needs of disabled children are met in accessing the best of health and rehabilitative care, education and social services, they will have an infinitely better chance of becoming productive, self-reliant individuals who contribute to their communities rather than becoming dependants on public resources.

Advocacy services contemplated by Bill 74 ought to be extended to include children under age 16, which is virtually the whole of the Easter Seal case load in Ontario. If this is done, it should also carry an amendment so that parents representing disabled children and being secondary consumers have proportionate representation on the Advocacy Commission and in the selection process of the appointments advisory committee. Provisions governing accountability of advocates, rights of entry and access to records should be revised to meet the needs of children. Parents and appropriate health care professionals should be consulted before any amendments or revisions affecting children are made.

I would like to address Bill 109. When parents learn they have a child with a disability, they take on the responsibility of raising that child with total commitment, dedication, self-sacrifice and always with the best interests of the child at heart. Parents are used to working as partners with the health care givers, the doctors, surgeons, therapists, psychologists or any other specialist identified as needed by their child. They are used to making decisions on required treatments, some of which have long-term benefits if administered at the appropriate time.

It is a rare child indeed who, when confronted with the barrage of necessary and sometimes frightening procedures and treatments, will not protest, perhaps hysterically, at the thought. I know I have had to on occasion actually hold my daughter down when she was younger because of some treatment that was essential to her, and talk to her sympathetically and all the rest of it, but I still had to hold her steady so they could do whatever treatment was necessary without hurting her. It is not easy to do, but we had her best interests at heart.

Bill 109 provides an environment in which a child, purely out of natural fear, can refuse treatment and create an adversarial situation between parent and child. The child is acting on impulse, with little cognition of the facts and benefits of the treatment. The parent is acting in the best interests of the child, having gone through a lengthy process of medical consultation and soul-searching.

I can give you a quick example of a family right now that is going through whether to have their child go through a rhizotomy procedure. This is a procedure that children with cerebral palsy often have that will improve their muscle tone and their ability to walk, and in some cases it is recognized that this treatment would work for them. Now, this family is going through a long process of research. They have seen the Hospital for Sick Children, they have been to the treatment centres such as Hugh Mac-Millan and Erinoak. They have gone down to the United States to consult with doctors down there. I would say they

have the best interests of the child at heart before they make a decision. This is what families are doing.

The procedures contemplated in Bill 109 are indiscriminate and apply whether the proposed treatment would constitute physical or psychological abuse of the child. It is the reasonable risk of harm or abuse from treatment, and not the wish of a frightened child under age 16, which should trigger the costly and invasive adversarial procedures between parent and child. The advocate intervention, the appointment of the lawyer, review board hearing and appeal to the courts which form part of the process can surely be dispensed with when we are obviously dealing with a natural reluctance on the child's part to undergo treatment. Again, the costs come in here, because if an adversarial situation exists, families are going to be forced, if the advocate gets a lawyer, to get a lawyer. Families cannot afford it, so what is going to happen?

The wish of the child should only be one factor to consider in determining whether mental or physical abuse will result from treatment. Even in an exceptional case where treatment may result in abuse or harm, an intermediate investigative counselling procedure should be available to the parent and the child. Should the potential for abuse exist, this is surely more appropriately covered in legislation designed to address child abuse.

Bill 109 as drafted has the potential of delaying treatment, disrupting hospital schedules—the way it stands at the moment, if children protest, the doctor may not be able to carry on with the treatment, might cancel surgery; it could be chaos in the health system—severely damaging the parent-child relationship and placing an additional emotional and financial burden on families who are already carrying more than their fair share. We ask you to please give serious consideration to the total impact of this bill on all levels of its targeted population. Thank you for your attention.

**Mr Chiarelli:** Thank you very much for your submission. I would like to ask counsel a question or two arising out of your submission. In particular, you rightly point out that the advocacy bill, Bill 74, specifically states under section 3, "This act applies in respect of vulnerable persons who are 16 years of age or older." Then when you go to Bill 109, consent to treatment, subsection 10(7) says, "This section also applies"—this refers to involving advocates in the process—"if the person is less than 16 years of age and has demonstrated a wish to give or refuse consent to the treatment on his or her own behalf."

I would like to ask counsel what the factors are that went into drafting the legislation that says it is okay to have an advocate for this one particular purpose, but not for the many purposes that this presenter has suggested it might otherwise be appropriate for.

**Ms Bentivegna:** The reason for the provision of rights advice in the Consent to Treatment Act is that if children want to make the decision, therefore feeling they have capacity, and if they are found incapable, they are given the same rights as an adult who is presumed capable but found incapable. Bill 74 was introduced before Bill 109; therefore, there is not the consistency saying that—the

exception for the provision of this rights advice by an advocate in Bill 109.

That is the reason for the difference, because one was introduced before, but the idea being that if the child or the under-16 is saying that they want to make that treatment decision, and then their capacity is assessed and they are found incapable, they are given the same opportunity to dispute that finding.

**Mr Chiarelli:** There is an understanding and an acknowledgement in Bill 109 that for certain purposes, someone under 16 could be considered a vulnerable person or a person requiring advocacy. I cannot make any logical conclusion, and I conclude that it is rather arbitrary that it is only in this one instance that the advocacy provisions of Bill 74 apply to children.

I share the concern as well that age is very arbitrary. Using an age in the legislation is a very arbitrary way of dealing with the situation. It is very possible, and it occurs very often, that a 13- or 14-year-old can be as mature as a 16- or 17-year-old, and a 16- or 17-year-old can be as immature as a 13- or 14-year-old. Certainly there should be criteria set rather than an arbitrary situation, because but for one day it is possible that the advocacy provisions would apply, and if you are one day short in a particular circumstance as an individual, you do not get the benefit of the legislation.

I guess my questions are (1) why is it appropriate under just that one circumstance in consent to treatment and (2) why is it so arbitrary as to set a fixed date?

**Ms Bentivegna:** With the fixed age there is that presumption, so that if you are 16 and over it can be presumed you are capable and there has to be reason to believe you are incapable. But you can also be found incapable; it can be rebutted. For under 16 it is the opposite. You are incapable unless you as a young person trigger the determination of capacity, and if you are found incapable, then you are treated the same way as the over-16. So it is used to provide some reference point for those using the act.

1410

**Mr Chiarelli:** But perhaps you can envisage an advocate, as contemplated by this legislation, working in the field, working on the ground, in an institution, a medical setting or what have you, confronting the situation of a so-called child who is 15 years, 360 days old and being handcuffed, and not being able to do advocacy for that particular child but for the fact that the child was not five days older. Do you not see how arbitrary it is and how you might be handcuffing the whole process?

**Ms Bentivegna:** All I can say is that under consent to treatment, it is a much narrower role that the advocate plays in giving rights advice, in telling the young person, in this case, they have a right to challenge the finding of incapacity and a right to go to a review board. That is the role that is circumscribed. It is not the broader role.

**Mr Chiarelli:** I guess I will cut to my last question, and it is kind of repeating the same question. You are talking about a responsible advocate in the field coming across a circumstance where you have a 15-year, 360-day-old child, and that advocate cannot exercise his or her judgement

to provide advocacy services because that child is under age. Do you not see that as being a significant impediment to the process?

**Ms Bentivegna:** I can ask my colleague on the Advocacy Act, but there is that cutoff that was made.

**Ms Spinks:** If I could just add something briefly, I think my colleague correctly delineated the difference between rights advice and broader advocacy, and with respect to the broader advocacy rule, the Advocacy Act is quite clear. The purpose under clause 7(1)(b) is "to provide advocacy services to help vulnerable persons to express and act on their wishes" and so forth. This is very much client-directed, and we have heard from a number of parents that for the advocate to act on behalf of an individual in those circumstances where the parents still have custodial rights and interests applying creates problems.

**The Chair:** Further questions?

**Ms Carter:** You state that you are very disappointed that Bill 74 excludes the most vulnerable group of our society. By definition, Bill 74 is setting up advocates to carry out the wishes expressed by vulnerable persons, not to act in their best interests as they see them, but to carry them out. Now, if we are talking about the children who are vulnerable, then are they really in a position to directly express their wishes and have them carried out by an advocate, because most of them do in fact have parents.

It may be that what you are really asking for is that the parents should be given more support and advice. It may be that this is something Ontario should be thinking about, but that would maybe come under a different act. But certainly it does not seem as though this act is particularly relevant in that case.

Conversely, you are expressing fears that under Bill 109, the express wishes of children might interfere with medical treatment and so on, which seems to be the opposite of what you are saying in connection to Bill 74. You seem to be asking for the children's direct wishes to be taken into account.

**Mr Dawson:** Bill 74 is potentially a good act, but we are just wondering why children are excluded from a service that is being provided to a vulnerable person, whatever that term "vulnerable" means. That has not been clearly defined. I would consider that children are certainly in that group. But our real concern about that is that by not being involved in the act, we are not involved at all in the process of selecting advocates. Yet when it comes to Bill 109—as Mr Chiarelli was saying earlier on, Bill 109 says now an advocate will be appointed for that child under 16. The parents would have no say in the selection process because they are excluded from Bill 74.

**Ms Carter:** Yes, though in connection with that I could say that section 15 of the bill does list the categories to be on the appointments advisory committee. There are only going to be 12 people on the commission and we have six categories here which are multiple categories. We are really looking at an impossible situation, trying to represent everybody who could be affected.

**Mr Dawson:** You cannot represent everybody.

**Ms Carter:** No.

**Mr Dawson:** I think all we are asking is that children be included in the Advocacy Act so that if parents need to advocate, whether on a systemic basis or whether just individually, they have the services of an advocate.

**Ms Carter:** Really you are saying that it is the parents who need the advocate rather than the child.

**Mr Dawson:** The parents on behalf of the child, the parent being the custodian or the legal guardian of the child. Yes. The child at three, four or five years old may not be able to stand up here and say, "This is what I need," but the parent can. The parent is speaking on behalf of the child, knowing the child, knowing the needs of the child.

**Ms Carter:** In which case you wonder why there is a need for an advocate.

**Mr Dawson:** The need is because parents really do not have the skills, the energy or the time to advocate, as I said in the presentation. Parents are burnt out. If you meet a group of parents, everybody is struggling because the stresses are far greater than with a normal family. You have your normal family stresses—

**Ms Carter:** That is understood.

**Mr Dawson:** —but these are all additional. The stress is totally different.

**Mr Wessenger:** I am interested in your statement where you said that surely this whole process of advocate intervention can be dispensed with when we are obviously dealing with a natural reluctance, on a child's part, to undergo treatment. I think it is clear that the intent of the legislation is not to have four-year-olds, six-year-olds or nine-year-olds, because of their natural reluctance, requiring an advocate to be brought in.

**Mr Dawson:** I am not concerned with that.

**Mr Wessenger:** At what age do you think children should have the right to have an advocate advise them with respect to questioning their incapacity?

**Mr Dawson:** It seems to me that the real purpose behind the act is to protect people from possible medical abuse, from having treatment that could lead to abuse. Most families are not going to jeopardize their children and put them in that situation. You cannot put an age on it. I have known 12-year-olds who are so articulate or so mature, and I think Mr Chiarelli referred to that about an 18-year-old who maybe is not. I do not think you can put an age on it.

**Mr Wessenger:** Really I think the intent of the legislation is to allow capable people to make decisions with respect to their own treatment, and I think we are trying to ensure that that take effect. Of course the mechanism that has been developed is this presumption with respect to 16. In common law, for instance, there is no presumption and the question to be determined is based on the individual child and whether he or she has the capability.

**Mr Dawson:** Right.

**Mr Wessenger:** Would you support more that principle of looking at the child?

**Mr Dawson:** The way it is working now with the common-law approach, there do not seem to be very many problems. I have not been aware, certainly in the disabled environment—I am talking about children—of any abuse problems to do with medical treatment. Obviously the common-law factors are there. A child of, say, 12 who is very articulate can make up his or her own mind about things. I am sure the parent is going to pay attention to him or her, as indeed do the doctors. In fact, many doctors will include these children in the discussion about proposed treatments.

**Mr Wessenger:** But let me just put the scenario of the 12-year-old or 14-year-old who wants to make a decision about his or her medical treatment, which is contrary to the treatment of the parent. To determine whether that child has the right to make that decision in that category, surely you then have to look at whether the child has the capacity to make that decision, would you not agree?

**Mr Dawson:** I would say the child has the parent to make the decision for him. Legally a child has a parent or a guardian until at least age 16 and all kinds of decisions are made.

**Mr Wessenger:** You would basically not support the right of the child under 16 to make a medical treatment decision on his own. Is that what you are saying? I just want to be clear.

**Mr Dawson:** Not strictly on his own. I think we should pay attention to what he is saying. I think it should be done in consultation. I referred to the fact that maybe we could find some other format for maybe a third party to come in, similar to the advocate suggestion that you have but without invoking the whole of Bill 109, just maybe somebody to arbitrate in the situation, to look at the pros and cons, the reason for the treatment, the benefits of the treatment, the negatives associated with the treatment and listen to both parties. You do not need to put the child and the parent in a strictly adversarial situation where both parties may have to hire legal counsel. That should not happen.

**The Chair:** Thank you, Mr Wessenger. Mr Dawson, on behalf of this committee I would like to thank you for taking the time out this afternoon to come and give your presentation.

1420

HOSPITAL FOR SICK CHILDREN,  
DIVISION OF ADOLESCENT MEDICINE

**The Chair:** I call forward our next presenters, from the division of adolescent medicine, Hospital for Sick Children. Good afternoon. As soon as you are comfortable, could you please identify yourselves for the record and then proceed.

**Dr Kaufman:** I am Dr Miriam Kaufman. I am from the division of adolescent medicine at the Hospital for Sick Children, and also an assistant professor in the faculty of medicine at the University of Toronto. With me are Dr Eudice Goldberg, who is the director of the division of adolescent medicine at the Hospital for Sick Children and who is also an assistant professor in the faculty of medicine at the University of Toronto; and Dr Françoise Baylis, who

is with the department of bioethics at the Hospital for Sick Children and who is a lecturer at the University of Toronto.

We are here today to speak to you about Bill 109, An Act respecting Consent to Treatment. The division of adolescent medicine at the Hospital for Sick Children agrees that there is a need for a unified approach to consent to examination and treatment in Ontario. We feel that much of what is in the bill is progressive and of benefit to adults, but we have concerns, both practical and philosophical, with the bill's approach to people under the age of 16. It is our belief that the arbitrary cutoff of 16 as the age above which one can assume capacity and below which one cannot, disenfranchises young adolescents. The assumption that they cannot take responsibility for any of their medical care is patronizing. To base a doctor-patient or therapist-patient relationship on an assumption of incapacity which must be rebutted changes the nature of that relationship in a very basic way.

Perhaps this effect can be more easily understood if you consider what would happen if this bill assumed incapacity for all native people and capacity for everyone else. A native person would go to his doctor, who would say: "I can't treat you yet. There's a law that says you're not competent to consent to treatment. I can rebut that but I have to ask you some questions to determine if you are really able to consent." This interaction makes it clear to the patient that all the power in the relationship is vested in the physician. The patient's own assumptions about his competency are called into doubt.

Much of the work that we do with youth is aimed at empowering them. We try to help them to take responsibility incrementally for their lives and to deal with and enjoy the ability to become autonomous. What kind of power can a person have who is assumed to be incompetent?

By specifying a certain age limit, you are essentially requesting practitioners to view all patients under 16 as being the same. This view is contrary to our knowledge of child and adolescent development. In fact, most adolescents under 16 are both cognitively and emotionally mature enough to give informed consent. Incapacity, with respect to consent to treatment, is definitely the exception and not the rule.

The basic issue that needs to be addressed in this legislation is the balance between the adolescent's right to good medical care and his or her right to consent to or refuse treatment. The balance between these rights must be maintained.

In drafting this legislation, recognition of the difference between capacity to consent to treatment and capacity to drive, vote or drink has been given. What must also be recognized is that the capacity to consent to treatment may vary from procedure to procedure. There is a spectrum of capacity to consent to treatment that the proposed legislation does not recognize, given that all those under 16 are to be presumed incapable with respect to all treatment. A 14-year-old may be competent to consent to acne treatment, HIV testing or birth control counselling, but not to refuse psychiatric treatment or chemotherapy.

A letter from our hospital to professor David Weisstub, chair of the Inquiry on Mental Competency, states with regard to the process to determine capacity:

"The rigour with which it is applied should increase as the risk to the patient increases. What we are suggesting is that in situations of low risk, that the process required is one in which the practitioner should be required to ascertain for himself or herself in some perhaps informal fashion that the person is competent to make the judgement that he or she is making. As the degree of risk increases, the process should be one in which there is a clear and careful documentation that an assessment of the person's competency to make the decision has been carried out."

The ability to consult a doctor and be treated without parental consent or knowledge is very important for an adolescent who is in need of confidential services. Examples of such services include birth control counselling, sexuality counselling, safer-sex counselling, treatment of sexually transmitted diseases and psychotherapy. Most teenagers will not seek treatment if they cannot be assured of confidentiality by their physician or if they even perceive that confidentiality is not assured. Also, although the notion of advocacy services seems on the surface to be an appropriate option, introducing a third party, perceived by the adolescent as an outsider, might be sufficient to drive them away from needed services.

As health care providers who deal exclusively with adolescents, we feel that subsection 8(2) will severely limit access to health care services for those under 16 years of age. Even though the proposed legislation allows for rebuttal of incapacity on an individual basis, there is the very real possibility that the perception by most teenagers and by many physicians will be that young people can no longer be assured of confidential health services. As has been the case in 16 states in the United States, where parental notification or judicial bypass have been instituted, major delays in treatment will occur and access to health care services will be adversely affected. This will not only affect individual youths but also result in increased costs to the health care system, with increases in teen pregnancy, pelvic inflammatory disease, AIDS and other preventable problems.

The proposed legislation, however, puts a particular onus on the health care provider to rebut a presumption of incapacity codified in law. Even if physicians practising adolescent medicine continue to provide confidential medical treatment to patients under 16, many others in Ontario will not do so. This will become particularly troublesome in smaller, rural or remote communities, where access to treatment for adolescents may already be limited. This legislation may allow those physicians whose own personal values oppose any expression of adolescent sexuality to refuse service, based on the assumption of incapacity. There is no incentive to rebut the presumption of incapacity in this legislation.

Further practical concerns regarding this proposed legislation include the following questions:

1. The present government has already endorsed anonymous HIV testing. How will Bill 109 be enforced when individuals are not even required to identify themselves? If

HIV testing and counselling become an exception to Bill 109, what differentiates this service from birth control counselling, acne treatment or other health care service that young people are seeking?

2. How will youth no longer living at home receive adequate medical care?

3. Under subsection 16(3), adolescents under 16 who have children of their own will not be able to consent to their treatment. Health care providers are trying to promote responsible parenting. Having a third party introduced to provide consent for examination and treatment to children of adolescents will impede this necessary developmental process. The availability of this third party for the frequent medical visits required for young children will be exceedingly difficult to guarantee.

We suggest the following:

1. Remove subsection 16(3).

2. Eliminate any arbitrary age limit for capacity to consent to all medical treatment and maintain what is currently in place through common law. Requirements for capacity to consent should be based on the relative risks involved in consenting to or refusing treatment.

3. Ensure that all advocates have specialized training in child and adolescent development and that they are all sensitive to the special needs of youth.

Just before our presentation we were made aware of a series of amendments that have been tabled, one of which we would like explicitly to endorse. It asks that section 8 of the bill be struck out and substituted by:

"A person is presumed to be capable to consent to treatment if he or she is capable of understanding the nature, purpose and consequences of the treatment."

We feel that this is a much better definition than any arbitrary age definition.

Further, if there are any other amendments to be proposed, we would appreciate being informed of these in a timely fashion so that we may respond. The implications of the proposed legislation are far-reaching and it is important that we have an opportunity to respond to them.

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**Mr Chiarelli:** I believe the amendments are Progressive Conservative amendments, not government amendments, that you may have been looking at. I do not think the government has shared or tabled any amendments at this point in time.

**Mr J. Wilson:** Just as good, though.

**Dr Kaufman:** I hate to agree with a Progressive Conservative, but actually it is a good amendment.

**Mr J. Wilson:** That hospital was funded so well and run so well under our government, I do not know where you people get these mythologies from. How you could support these two parties is beyond my comprehension. Have you not seen the province go down the toilet in the last seven years?

**The Chair:** Order, please.

Interjections.

**The Chair:** Order. Mr Chiarelli, you have the floor.

**Dr Goldberg:** We would hope that political differences would not stand in the way of a very important piece of legislation and that no matter which party said what, I think I, along with Dr Kaufman and Dr Baylis, feel strongly that there should not be an arbitrary age for consent.

**Mr Chiarelli:** I appreciate the comments in your brief and I appreciate the experience that you are bringing to the table. I think frequently legislators have notions and principles which they want to enshrine in legislation and we do not always translate that into how it is going to work on the ground. What I would like you to do for me and the other committee members is to describe, perhaps by using one or two examples, what would happen in your hospital, how treatment is delivered and how medical practitioners act, if this legislation were to pass as written now. What would happen in the clinics, in the examining rooms etc that you feel is unpalatable?

**Dr Kaufman:** I think we should probably both speak to this. Speaking for myself, if this legislation is passed I will ignore it in terms of assuming—I am not going to ever assume that my patients are incapable of giving me consent and that they are incapable people, because it will completely change how I deal with them.

My concerns are much more for what is going to happen outside our hospital, where people are perhaps not as attuned to the best interests of these kids, and that outside when someone comes and says, "I'm thinking of having sex with my boyfriend, can I have some birth control?" a physician will say: "You know, you're not capable of giving consent to that. I can't even tell you about it because that's also treatment, but we can go through a whole process to find out if you're capable." The kid will then say: "Forget it. I already waited 10 minutes out there in the waiting room. That's too long. I'm leaving."

**Mr Chiarelli:** But presumably your hospital is going to set some guidelines to operate under for this legislation.

**Dr Kaufman:** Yes.

**Mr Chiarelli:** What do you anticipate those guidelines will be and do you think everybody will be like you and just ignore them?

**Dr Kaufman:** No.

**Dr Goldberg:** I think it will create absolute chaos, because I do not know how this particular piece of legislation can be implemented. Our area of expertise is in dealing with teenagers, so I would rather restrict my comments to that, although I know that certainly this will have a great impact on delivering health care to younger children as well.

I think the greatest danger with this legislation, no matter what the intent, as good as the intent may be in the legislation to provide advocacy for people who are presumed to be incapable of giving consent, is that the perception of teenagers will be that they can no longer access confidential health care services. They will come in pregnant when they are 30 weeks and about to deliver. It is just horrendous what can ultimately occur. Kids who do not feel they can share information with their parents will not go to see doctors or other health care providers, and I think there is a real danger out there for teens to just be driven underground.

**Mr Chiarelli:** If I can just ask one follow-up question very quickly, when the government introduces an amendment to delete subsection 10(7) regarding 16 years of age and under and capacity, and we go back to the common law, could you tell me what your understanding of the common law is, under these circumstances?

**Dr Goldberg:** My understanding is that when I see patients, I discuss with them what it is that I am about to do and I try to arrive at some assessment as to their understanding of what it is that we have discussed. That understanding is what is vital for them to be able to give informed consent.

**Mr Chiarelli:** Thank you.

**Mr Poirier:** You are not the first health providers to come forward with this exact type of statement. You do not need to be a philosopher to understand it. Even myself, as a Capricorn, as a very logical animal, I understand that there is a hell of a lot of logic to it, and it is not hard to understand whatsoever. It is not hard to put ourselves in your shoes as to what the hell do you do with that kind of situation. When we know what is happening with the young people out there, with the difficulty of communications with the family even in 1992, if this is going to shut the door on access to health treatment for kids under 16, I cannot help but be convinced that my friends in government have listened to your and other health providers' proposals for age 16. I know that the legal counsel has also been listening.

I am confident as I look at the fine parliamentary assistant that, even though he says the minister is going to wait to the end to listen to all the proposals, I cannot help but think that either they or we shall bring forward an amendment to respect that type of proposal. I just want to say thank you for coming forward and saying it in very well-put words and I just hope that I get a chance one day to go in front of the board for an excellent hospital and myself make a proposal for a much better name change for that horrible Sick Kids and call it the Children's Hospital of Toronto. I do not know why they would not call it healthy children or whatever, but I hope one day to return the favour and give you a good proposal for change of name for your hospital.

**Dr Kaufman:** It has a certain historical appeal.

**Mr J. Wilson:** Appropriately named, I suppose, under a Conservative government at the time. All kidding aside, I do appreciate the support of the amendment. We brought forward the amendment to try and advance these hearings. We have had other groups raise this point. The parliamentary assistant, when he gets his turn, will likely tell you that the government is very concerned about this and is going to do something about it. It seems to us that it would make sense for the government to bring forward its amendment now, so we would not have to take up your time and our time debating things that there seems to be all-party agreement on.

That is why we took that step. It is not an unusual step and, in fact, it is a responsible step that we have taken for many, many years in introducing amendments as the process

goes and not saving them all up in the devious way in which this government operates.

I do have a serious question about HIV testing. I think you raise a very good concern. The government has endorsed anonymous HIV testing. I do not know what percentage of people under the age of 16, or how many people are now taking advantage or using the service of anonymous HIV testing. I would be interested to know whether you are aware of those statistics. Second, I would ask the parliamentary assistant whether they have thought this one through in terms of this legislation. I am sure it is not the intent of the legislation, but I would ask for the parliamentary assistant's comments in this area of HIV testing, and my hope would be that this legislation would not in any way impede the anonymous testing of people under the age of 16. I do not know if either person would be aware of the extent of the testing under the age of 16 now, either the witness or the government.

**The Vice-Chair:** Would you care to answer that, Mr Wessenger?

**Mr Wessenger:** I am not aware of the situation with respect to the number of children who are being tested for HIV anonymously, since it is a new program that has just been introduced.

**Mr J. Wilson:** That is fair.

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**Mr Wessenger:** I do not see that the test of capacity would be any different for that than any other situation in respect to testing. So whatever is determined under this legislation would apply to the HIV testing.

**Mr J. Wilson:** I think it does because what if you have a child who is under the age of—a person, I do not consider someone under the age of 16 as a child—a person under the age of 16? Anonymous HIV testing is crucial especially if that person is involved with drugs. He may not be lucid. He may be considered incapable by an attending physician. Do the witnesses have any comment on that? I do not think that would be a far-fetched scenario, would it?

**Dr Kaufman:** If we judge that somebody was incapable to give consent, then Bill 109 does not really apply because whether there is an age limit or not, if somebody is not capable to give consent, we do not let them give consent. We do not have numbers on how many kids are going for anonymous testing. All of the testing in our clinic is done nominatively, but we do refer kids occasionally for anonymous testing.

**Mr J. Wilson:** I thought part of the point was that bringing in an advocate at that point might discourage people from coming forward for anonymous testing.

**Dr Goldberg:** By definition, the testing cannot be anonymous if we have this information about them: We do not know their names and yet we are asking them their ages? You cannot obtain that kind of information when you are doing anonymous testing.

**Mr Wessenger:** Can I just follow that? You still have to determine the question of whether they are capable. If an incapable person wanted to be tested, you would still

have to determine if he was capable. If he was not capable, then you would have to get the consent of a substitute decision-maker.

**Dr Kaufman:** Yes, but we are saying we would like to be able to make the same assumption of capacity with people under 16.

**Mr Poirier:** It is not a question of age.

**Mr Wessenger:** Thank you for your presentation. I have certainly appreciated your frank statements and I would also like to compliment you on applying the common law with respect to the question of capacity. It is encouraging to see that, you know, you are looking at applying it properly in this regard.

**Mr Poirier:** If only the law had common sense.

**Mr Wessenger:** Yes, I like to compliment that approach. With respect to your suggestion concerning subsection 16(3), I understand why you would like it eliminated. I assume the reason you want it eliminated is because of the situation of a parent under 16 consenting for his or her own child. But would you object if, instead of being eliminated, it was merely amended to allow the consent in those circumstances, because I think there are other aspects. For instance, a child under 16 consenting on behalf of a parent might be considered objectionable on the one hand, while it would be quite acceptable for a child under 16 consenting on behalf of his or her own child.

**Dr Kaufman:** Certainly our concern was for adolescent parents. Somebody asked about practicalities: I have a clinic for babies of teen mothers and it would be a real disaster if somebody else—so we would really appreciate an amendment.

**Mr Wessenger:** So you would like that particular problem addressed.

**Dr Kaufman:** Yes.

**The Chair:** Dr Baylis, Dr Goldberg and Dr Kaufman, on behalf of the committee, I would like to thank you for taking the time out of your busy schedules to come and give us a presentation today.

#### CATHOLIC HEALTH ASSOCIATION OF ONTARIO

**The Chair:** I would like to call forward our next presenters, from the Catholic Health Association of Ontario. Good afternoon. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Mr Marr:** Good afternoon. My name is Ron Marr. I am the president of the Catholic Health Association of Ontario. I want to thank you first of all for taking the time to meet with us today and to let us express some of our views on the proposed legislation which is under review by this committee.

Before getting into details of the review, I would like to take about 30 seconds, maybe one minute, just to tell you who we are and to put in perspective a little bit of where some of our views are coming from on the proposed legislation.

The Catholic Health Association of Ontario was founded in 1931 and is a voluntary association of persons and individuals involved in the Catholic health ministry in

the province. Our association has a very diverse membership consisting of a number of hospitals and homes for the aged, nine religious congregations of women who own and operate and sponsor health facilities in Ontario, the Ontario Conference of Catholic Bishops, representing the Catholic bishops of the province, and a large number of individual personal members. The institutional sector of our membership base consists of 27 acute and chronic care hospitals, five hospitals with both acute and long-term care wings and five freestanding homes for the aged. Our members are representative of most regions in the province both in large rural areas and smaller urban centres. We are one of the few—if not the only—voluntary associations in this province which focus on health and health cares services in their broadest definition and include both acute and long-term care emphasis.

The first Catholic hospitals in Ontario were established in 1845 in Ottawa and Kingston. Today approximately one in seven hospitals in Ontario is Catholic and we operate approximately 8,000 or 16% of beds in large teaching hospitals, local community hospitals and smaller rural hospitals. Catholic long-term care centres operate approximately 1,800 residential and extended care beds, and among these institutions sponsored by the Catholic church, we employ in excess of 24,000 staff and have operating budgets greater than \$1.7 billion per year.

Over the last number of months, the task force for our association has examined very carefully both the intent and content of the draft legislation being considered by this committee.

In general, we are supportive of the legislation and its efforts to protect the vulnerable individuals in our society and to permit individuals to make health care treatment decisions which will be respected in the event of their incapacitation. However, we do have a number of concerns and recommendations we would like to share with you today.

Speaking to you first today will be Sister Kateri Ghesquiere. Sister Kateri is a member of our board of directors and is also the assistant general superior of the Sisters of St Joseph of London, Ontario. She serves on the board of St Joseph's Health Centre of London, St Joseph's Hospital in Sarnia and St Joseph's Hospital in Chatham. Sister Kateri will address the issue of the role of families in this legislation.

Speaking second will be Mr Dan Faulkner. Dan is the vice-president of the Catholic Health Association of Ontario and has particular responsibilities for working with our members in monitoring legislative initiatives by this Legislature. Dan will address the issue of the mission of the institutions, research and public education.

At the conclusion of their presentations, we would be very happy to answer any questions you have. I will call on Sister Kateri to begin discussing her concerns.

**Sister Ghesquiere:** The members of the task force that examined this legislation, the executive committee and the general membership of the Catholic Health Association of Ontario realize that the legislation proposed in Bills 74, 108, 109 and 110 covers a number of subgroups which have been given the general designation of vulnerable persons, in particular, that subgroup previously protected

by the Mental Incompetency Act. Since some of these persons are at times institutionalized and/or do not have close family ties, it is most appropriate to make provision in those cases for other than family members to consent to treatment, and most appropriately, great care has been taken to ensure that all their rights are respected. Other circumstances also exist, such as mine as a member of a religious community, where family members are not the best informed as to personal wishes in the case of illness. I personally intend to take advantage of the legislation to designate an attorney for personal care, even though the provisions of Bill 108 would make it ineffective in an emergency situation.

However, given the initiatives of the past and present governments of this province, especially as most recently expressed in the consultation paper on the redirection of long-term care and support services in Ontario, an increasing number of persons will be cared for by immediate family members.

It is with this in mind that we applaud the objective in Bill 74 to acknowledge, encourage, and enhance individual, family and community support, but we are grieved to find instances when the family is distanced or even denied participation in the decision-making process and a complex procedure required of both health practitioners and health care facilities to initiate treatment. I know media attention and other presentations to this committee have also pointed this out and I will not dwell on examples. However, it does seem appropriate to make a general comment that these pieces of legislation do seem to be more pertinent to long-term disabilities than to those incapacities associated with trauma situations and/or incapacity that comes from acute illness, especially in the more senior segment of our population.

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To make direct reference to our brief, on page 6, I would point out that according to the letter of the legislation, regardless of its spirit, decision-making is very quickly put into the hands of the public guardian and trustee, with the validated power of attorney being mentioned but family very seldom, if at all. Numerous persons are entitled to information resulting from the advocate's findings and recommendations, but not the family, and there is no mention of an appeal mechanism.

Bill 74 mentions in two places respect for cultural diversity, but nowhere in the legislation is any specific safeguard of this cultural heritage put in place. The culture of the guardian and/or trustee and/or attorney would, by implication, have more influence than the culture of the vulnerable person, unless specific written instructions have been given.

I would like to make reference again to those persons who either do not have closely related persons who would be cognizant of the person's wishes or who prefer to have someone outside the family as their substitute decision-maker.

This legislation provides the possibility of a power of attorney for personal care being designated while the person is capable of making such decisions. However, this power of attorney must be validated after the person becomes incapable. Instructions contained in the power of attorney

can be followed. It is unclear to me whether this is before or after the advocate has judged incapability. But to expect a person to anticipate all possible areas of treatment is unreasonable. If I know I am in danger of a heart attack, I may provide for possible treatment options, but not for kidney failure or pneumonia or some other disease.

If a substitute decision-maker is to be a comfort to the person who is perhaps aware but not capable of expressing wishes and be of assistance to the health practitioner, then the automatic intervention of an advocate must be re-examined.

**Mr Faulkner:** In addition to the issues Sister Kateri has just described, the CHAO is also concerned with the potential threat to the mission of health facilities under the current language of these bills.

As a provincial association with a diverse membership consisting of Catholic hospitals, both acute and chronic homes for the aged, nursing homes, religious congregations which sponsor these facilities and the Ontario Conference of Catholic Bishops, we devote a lot of our organization's time to the maintenance of the mission and philosophy of health care institutions. Over the years, religious congregations have brought their shared value system to many communities across the province, often at the request of a community, to respond to unmet needs, and this began a long history of compassion and caring in Catholic health facilities, particularly serving the poor, the elderly and the vulnerable. These values and philosophy are an integral component of the mission of the facility, which are then translated to governance structures, management practices and right down to the day-to-day activities of each institution. To try to summarize these values in one or two sentences is very difficult, but it would include a respect for life from beginning to end and an emphasis on holistic care, and that is treating the whole person, physically, emotionally, spiritually and socially.

We are the largest group of all the denominational health care facilities in the province. They, as well as all the non-denominational institutions, have a mission based on their founders' values and beliefs upon which all their activities are patterned. We are concerned that Bills 108 and 109 in their present form may legislate behaviour on the part of health practitioners which would impinge on the freedom to act within the mission of the facility.

Specifically, Bill 108, subsections 63(1) to (3) and section 66, which outline the duties of the guardian and the attorney under the power of attorney, state that the decision-maker will act in accordance with any wishes expressed or any instructions contained in the power of attorney. In Bill 109, section 4, the health practitioner will be legally obligated to fulfil those instructions or wishes upon receipt of direct consent from the person or the substitute decision-maker. This wording provides no degree of flexibility for institutions and the professional staff to accommodate a patient when his advance directive is in the form of either wishes or written instructions that are inconsistent with the mission of that institution.

Our recommendation to this committee is to amend these sections in a way that will not take away an individual's empowerment to make health care decisions for himself, but to incorporate some degree of flexibility

for the institution in situations where these instructions may compel a facility to compromise its philosophy. In fact, wording of this nature appears already in Mr Sterling's Bill 8, An Act respecting Natural Death, in subsection 6(3), which provides for the transfer of the care and treatment of a patient by a health care provider who is unwilling to comply with that person's living will instructions.

I would like to affirm that we do realize these bills have not been drafted to legalize euthanasia, but there does seem to be a growing misconception among the public that this is in fact the case. We suggest extensive education initiatives occur not only for the public but also for the health care practitioners who may have to alter their current practice patterns to conform with the legislation and the associated bureaucracy that will arise.

We are equally concerned with the combined effects of Bill 108, subsection 47(6), and Bill 109, section 15, which completely exclude consent to a procedure whose primary purpose is research unless the person's power of attorney expressly provides instructions to comply for specific research procedures. In reality, many people will not have a power of attorney for personal care, and of those who do, the number which contain explicit instructions to consent to procedures for research purposes will probably be rare. CHAO is concerned that valuable research will not be able to proceed, particularly with young children, who are considered incapable under these bills.

I must emphasize that we do not wish to impart discretionary powers to health care practitioners with respect to research participation and consent, but there are many projects which are non-invasive, with minimum to no risk, which will not be allowed to occur on individuals who are deemed incapable under this legislation. In situations such as these, we do support research activities which are a potentially direct benefit to the incapable person or advances the interests of a particular population.

Therefore, we ask this committee to review this part of the legislation and revise the wording to accommodate research guided by the following principles: There must be no alternative population available, the research must be of minimal or no risk and the appropriate substitute and informed consent is given. Adhering to these guidelines will permit valuable research to continue on vulnerable persons, particularly children, which poses no threat to their wellbeing, maintains the requirement for informed consent from a parent or substitute decision-maker and advances society's ability to control or prevent many diseases and disorders for which we currently have insufficient knowledge to do so.

Thank you very much for your attention and the opportunity to appear before this committee. We would be very happy to entertain any questions you might have at this point.

**The Chair:** Thank you. Questions or comment, Mr Poirier.

**Mr Poirier:** I guess you were here for the previous presenters about the age of consent being 16. Does that cause you a specific problem or is it the same type of

problem in your hospitals as in the general non-Catholic hospitals?

**Sister Ghesquiere:** Yes. We did not particularly address that because our concerns were more with families and particular points where we perceive some threat to the mission, but we certainly realize that it is rather arbitrary to say that at 16 a person is capable or incapable.

**Mr Poirier:** Would you have some specific recommendations to make pertaining to that? Have your health care providers mentioned that to you? Have they mandated you to come forward with a recommendation as to how you feel about that?

**Sister Ghesquiere:** I happen to know that at least one group will be presenting before you, I believe later this week, mainly on the area of research, but I think they also address that age of consent.

**Mr Poirier:** I realize your point about family, but unfortunately, as we see today, there is less and less family. There is not your vision and my vision of what we would like to see in society, but between our wish and the reality out there, I guess you in hospitals, and we here, have to deal with families that are not families, as much as we would like to see it. When young people under 16 come into your hospital and seek treatment—for example, pertaining to the case that was described concerning the Hospital for Sick Children—what happens in your hospital when the child who is 14 or 15 comes in and wants advice on health issues that may not fit in with your mission, with a capital M? What happens there?

**Sister Ghesquiere:** We have discussed this at length. I cannot say what happens within the private office of every health-care practitioner. We ask those who work with us to realize what our mission is, what the general teaching of the Catholic church is, and then to use their own consciences to apply that when they are dealing with an individual person.

1500

**Mr Poirier:** So in theory, if that is the case, a 14- or 15-year-old girl coming in, or a boy wanting protection for birth control or sexually transmitted disease, can get that same type of advice from a health-care provider if he or she feels that it goes along with his or her conscience.

**Sister Ghesquiere:** Theoretically, yes. I would not be able to answer in the practical.

**Mr Chiarelli:** Thank you very much for your brief. It is very comprehensive and well-thought-out. I note here in your brief that you represent 16.5% of the beds in large teaching hospitals, which reflects, I think, over 8,000 beds. You are obviously very interested in this legislation. It is going to impact on you or your member facilities in a very major way.

Do you see any serious problems in the implementation if this legislation goes ahead as is? Previous presenters, in one case Dr Kaufman I think, said that she will ignore the legislation, and in the other instance her colleague doctor said that it would create chaos. What is your perception, understanding of the whole health-care area, as to how this legislation will work in practice?

**Sister Ghesquiere:** The doctors I have spoken to are really concerned with people presenting themselves, especially in the emergency room. I know that they are presently very careful with respect to consent and have very careful policies with respect to consent. The family is always respected with respect to consent. There are concerns with the fact that they will no longer be able to accept the consent of the close family member, that the family member, under these bills, has at most questionable authority.

**Mr Chiarelli:** There was one particular point that was made concerning the requirement to give treatment if capacity is found. Did I understand you to say that because of the philosophy of some of your institutions you feel that you would be forced under this legislation to provide certain treatment that you otherwise would not be providing by choice? I am thinking in terms of somebody coming in and saying: "I have capacity. I want to have an abortion performed on me." Are you concerned about that element of the legislation?

**Mr Faulkner:** Yes. If we are to take an extreme case of abortion or euthanasia—it seems to be a very hot topic these days; it is being discussed across the country at the federal-provincial level—if at some point in the future euthanasia is given much wider latitude or perhaps even decriminalized, then the bills as they are written now will obligate the health practitioner and the facility to follow those wishes of that person, if that is what they want.

**Mr J. Wilson:** Thank you very much for the presentation. Just to follow up with the comments and questions by my Liberal colleagues, I am very much aware of the missions in Catholic hospitals, for instance. My family has a long involvement at St Michael's Hospital—indeed, I was born there. It does not make me an expert, but it does help. Dr J. K. Wilson is my great-uncle, who served there for many years.

Interjection.

**Mr J. Wilson:** Yes, the halo is tarnished, I am sure.

Following on the questions of Mr Chiarelli—that is an extreme case perhaps with euthanasia, although not unfathomable now with the way society is going—do you have any more practical examples, just to give people a feel for what the mission is and how power of attorney for personal care may at times contain instructions contrary to the mission of St Mike's, for example?

I think an example of the strong Catholic ethos is when a patient goes to St Mike's, for instance, to give birth, the doctors, following the ethos of the hospital, it is my understanding, would always deem there to be two patients, to do the utmost for both patients if there were complications in the birth. Somebody brought this up to me. They brought this forward the other day as an example where there may be some conflicts under the act. For the world of me I cannot remember the argument. I am just wondering if you thought of that, where there would be conflicting rights of patients.

**Sister Ghesquiere:** I am not sure that that comes under the auspices of this act. I had not looked at that, because that is a capable person. I suppose it could be

argued that the infant is not a capable person. I am not sure what the advocacy would be here.

**Mr J. Wilson:** You know, we are having the Ontario Coalition for Abortion Clinics right after you on today's agenda. I think the question for the government under this act is, when is a person entitled to protection under these acts? The previous group especially asked for advocacy services with no age discrimination. Anyway, we will not get into it here. It is a question perhaps for an ethics committee as much as anything.

I do very much appreciate your recommendation on page 12, recommendation 9, that prior to implementation a cost evaluation be done. I mention that to bring it to the attention of the government, because I am meeting tomorrow with the president of St Mike's, or the outgoing president from St Mike's, as the Health critic for my party. It is a question I have asked many presenters, because it seems to me that in their presentations we often find that the underlying problems are that there are not enough community resources. We had a senior citizens' group saying, "The advocate is going to make sure I get a hospital bed." "Well, there is not a hospital bed for you."

So do you want the \$46 million to go to an advocacy system, or would you rather we had the services out there that we pretend we have and that are rapidly declining? I very much appreciate that recommendation and want to flag it for the government's comment and certainly attention.

**Mr Winner:** I just wanted to address with you a couple of small technical points you raise in your brief. The first is at page 11. You point out, just about a third of the way down the page, that there is no mention of the grantor's death in a power-of-attorney situation as a means to discharge the power of attorney, as there is in the case of a power of attorney for property. I just wanted to point out to you that in the situation of an attorney for property, if the grantor of that power dies, the property still exists, so you need a provision to deal with terminating the power of attorney so that the will can kick in or the laws of intestacy can kick in. But where the grantor of a power of attorney for personal care dies, there is no one left to care for, so there are no acts that really need be addressed and the reason for a termination is not necessary there.

Then again on page 12, you indicate that there may be some inconsistency between section 15 and the Consent to Treatment Act, which appeared to disallow research on incapable persons. Last week we had some clarification on this—you can read about it in Hansard—that section 15 does not change the law with regard to research on incapable people. So that if there is a power of attorney who consents to research with explicit instructions, that can still be executed. Section 15 does not prevent that from happening.

1510

**The Chair:** Thank you, Mr Wessinger. Er, thank you, Mr Winner. My apologies.

**Mr Wessinger:** Yes, we get mixed up. We are both lawyers.

I was interested in your concern about any interference with your mission statement. What I would like to suggest to you is that really, in this legislation, we see nothing that

restricts the right of a health practitioner from transferring the care of a patient whose wishes are instructions that the health practitioner cannot follow. We suggest that is open to the health practitioner to do that, so we do not really see that we interfere with your mission's statement of your institution.

**Mr Malkowski:** Thank you for your excellent presentation. I want to clarify a point on page 7 where you refer to the advocacy, the making of findings, and recommendations on advocacy under Bills 108 and 109, and to provide an explanation. Also, if a person wanted to challenge or contest those findings under incapacity, what would be your concern so far under the advocacy with not making the decision on that for that person? Could you explain that, please?

**Sister Ghesquiere:** I think the view of the task force that studied this was, when we put all the series of laws together, it seemed to be very complex on where the family could have any import. The advocate comes in; we realize there are times when the advocate is necessary, but then the family seems to be completely removed from the situation. We thought, as a very minimum, that there should be some right for the family to perhaps discuss or maybe even contest the findings of the advocate, and we could not find that in the bill.

**Mr Malkowski:** May I just clarify again here? The point is the advocacy: It is very clear that advocates do not make decisions for a person. That is very clear. They simply pass on the options and follow the instructions and wishes under the consent to treatment, as also the rights advice. That is all they function as. It is a very limited role.

**Sister Ghesquiere:** We did not see that clarity in the legislation.

**Mr J. Wilson:** But you are right. The advocates come before the panel. The advocate would be there before the family even knows what is going on.

**Mr Malkowski:** I just wonder if I could refer to the legal counsel to clarify, please.

**Ms Spinks:** No, I was just curious when you refer to findings and advocates making findings and decisions to what precisely you are referring.

**Mr Chiarelli:** Last week I asked a question of the legislative counsel in the situation where there is a person under 16 years of age, where there is a finding of incapacity or a feeling of incapacity on the part of the medical practitioner, or they are not sure whether a person has capacity to instruct or not, that an advocate must be involved. The answer last week was that there is a legal obligation to involve the advocate under those circumstances; there is no legal obligation to involve a parent. So that if I as the parent of a 14-year-old have that child brought to an emergency room, or to some health-clinic setting or what have you, and there is the determination of incapacity for whatever reason, the legal obligation, as I understand the advice last week, is to involve an advocate, who most likely is a stranger, and there is no legal obligation to involve a parent.

**Ms Spinks:** If I could just respond briefly. That is correct, and I am certainly not contradicting my colleague.

But I think that is an entirely separate matter from referring to an advocate as making a finding and that this finding should be open to appeal, because there really is no finding with the involvement of the advocate.

**Mr Chiarelli:** What I am trying to do is emphasize the issue that there is the factor of the family being less included than more included in this legislation. That is one of the concerns of these presenters and is another example that I have pointed out where the family, in a sense, is being excluded legally. From a practical point of view, I would imagine that a medical practitioner would get the family involved, or at least call the family, but there is no legal obligation. If you look at the strict terms of the law, there is a requirement to get an advocate involved, but no requirement to get the family involved under those circumstances.

**Mr Malkowski:** I just need to clarify again, Mr Chair. I think the opposition misunderstands. There is a different issue here. I would like to ask legal counsel to clarify the issue again.

**Ms Spinks:** I think it has been clarified. We probably both agree that the advocate is not making a finding or making a recommendation and so we are not in dispute on that issue.

**The Chair:** One further clarification, Mr Wessinger.

**Mr Wessinger:** I would just like to clarify that under the Consent to Treatment Act, if the person does not specify in a power of attorney or a guardian etc, the family makes the substitute decisions. It is first a spouse, then a child, parent, brother or sister in that order of preference. It seems to me the family is very involved.

**Mr Chiarelli:** But the advocate is called in first.

**The Chair:** Mr Marr, Sister Kateri and Mr Faulkner, on behalf of the committee I would like to thank you for taking the time out of your busy schedules to come and give us your presentation. Thank you.

#### ONTARIO COALITION FOR ABORTION CLINICS

**The Chair:** I would like to call forward the next presenters from the Ontario Coalition for Abortion Clinics. Good afternoon. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Ms Jones:** My name is Miriam Jones. I am a member of the coordinating committee for the Ontario Coalition for Abortion Clinics. With me is Sara Ballingall, who is a member of OCAC and a recent high-school graduate.

The Ontario Coalition for Abortion Clinics was founded in 1982 to organize for the legalization of community abortion clinics and the repeal of criminal laws on abortion. We, and the majority of Canadians, according to every reputable poll, believe that abortion is a crucial matter of personal choice for women, a vital precondition of women's reproductive health, sexual freedom, moral integrity and full and equal participation in society.

However, we have never been solely concerned with ensuring free and equal access to abortion. We know real choice can never be free in a society in which women face pervasive discrimination and violence, earn so much less than men and are systematically denied access to power and opportunities. We consider ourselves to be part of a

broad reproductive rights movement involved in a number of interdependent struggles—from access to safe and effective contraception to the right to define and live independent sexualities—which must be fought and won for women to control their bodies and their lives. We also believe that improved access to reproductive health care must go hand in hand with social policies that support women when they have children. This means enhanced prenatal education, universal day care, parental leave, community midwifery, affordable housing and economic equality for women.

We are here today because of our general commitment to equitable access to comprehensive health care. We applaud the basic direction of this legislation and believe these bills, combined of course with adequate resources, can contribute to health care that empowers individuals.

We have one crucial concern with the legislation, and it is this vital point we want to address here. We believe the age restriction in section 8, which creates 16 as the age of capacity to consent, constitutes an unnecessary and arbitrary barrier to equitable access to health care. It may hinder and prevent young people from receiving such vital services as birth control, pregnancy testing and counselling, abortion, and testing and treatment for sexually transmitted diseases.

We understand you are hearing from public health officials, experts and various health care providers. We will not repeat their specific concerns and arguments, but their main themes have been: first, while the legislation allows rebuttal of the presumption that anyone under 16 is incapable of giving consent, it is not clear what the rebuttal process entails; second, in the absence of clear guidelines, many health professionals could be intimidated from providing services because of the uncertainty about their responsibilities and liabilities; third, even if an explicit rebuttal procedure is established, many professionals simply may not bother to go through with it; fourth, regardless of the patient's understanding and their actual physical, emotional and overall development, there is concern that many doctors will not want to risk providing services. In effect, whether intended or not, age 16 may simply function as an arbitrary cutoff. We want to offer a cautionary note from our particular experience as one of the leading pro-choice organizations.

1520

The extensive cutbacks to abortion services that occurred in the wake of the federal government's attempt to recriminalize abortion offer a graphic and instructive parallel of what physicians can do if they feel they are at all legally vulnerable. Bill C-43 passed the House of Commons in May 1990. Physicians feared they would be charged under its provisions, which placed the onus on them to form a judgement as to whether an abortion met the prescribed criteria and should be allowed. Massive cutbacks in abortion provision began in Ontario and across the country at that time.

In November 1990, OCAC participated in a Ministry of Health consultation on access to abortion in Ontario. We documented the situation at that time, a situation which subsequently deteriorated even further as follows.

First, leading medical organizations such as the Canadian Medical Association and the Society of Obstetricians and Gynaecologists of Canada had consistently said that a large proportion of the relatively small number of doctors who provided abortion services would stop. A survey conducted by the Society of Obstetricians and Gynaecologists of its members found that 275 would stop providing services if the bill passed. That number was 59% of its members who currently provided abortions.

Next, many physicians had already stopped or cut back on providing abortions. The result was that many communities had fewer or no services. All four doctors providing services in Sault Ste Marie stopped. No doctors in Waterloo region had been taking abortion referrals since Bill C-43 passed the House of Commons. Doctors in Brockville, Oshawa, north Peel, Mississauga, Brampton and York region had stopped. Women from these and other underserved areas were being referred to Toronto and Hamilton. But even in Toronto there were increasing delays. The Bay Centre for Birth Control, the centrepiece of the previous government's reforms to speed up the process of referrals and provision in Toronto hospitals, had three-week waits for even an initial assessment. Growing numbers of general practitioners were refusing to refer their patients to gynaecologists for fear of prosecution.

We must remember that these extensive cutbacks all took place before the abortion bill was ever passed by Parliament. It had still to be passed by the Senate. Thankfully, as we all know, it never was passed. In fact, it was clear many more providers would be cutting back their services were the legislation to come into force.

The fragility of access to abortion speaks to the ease with which so many doctors abandon their responsibilities. There is little reason to think that physicians in general would be more committed to serving the sexual and reproductive health of young people. The experience of abortion provision underlines concern that doctors will simply stop providing services to young people as a result of this bill.

Sara will now talk about the consequences of this legislation for young people's health.

**Ms Ballingall:** The input you are receiving from public health officials and front-line providers emphasizes the serious impact on young people if access to sexual and reproductive health care services and counselling is restricted. The results can include higher rates of teen pregnancy, STD infection, abortion, pelvic inflammatory disease, infertility and low-birth-weight babies. Each of these involve critical physical, psychological, social, emotional and economic costs, both to the young people themselves and society at large.

The erection of unnecessary barriers to young people's access to health care and the consequent effects on their health contradict the preventive policies that underlie public health programs. We also note that public health officials have expressed concern that section 8 will also restrict access to counselling and education programs more generally.

To sum up, we believe that fundamental principles within which health care should operate are contradicted by section 8. The principle of equal access to the full range of vital services is threatened if doctors restrict their provision of

services to people under 16. The progressive policies of health promotion and preventive programs may be denied to young people, with potentially devastating short- and long-term consequences. The fundamental principle of empowerment, in which individuals have all the information and resources needed to make the key decisions to manage their own health care, is arbitrarily denied to young people.

**Ms Jones:** The many social, economic and cultural barriers to young people's access to sexual and reproductive health care are well known, yet Bill 109 as it is currently proposed creates a further unnecessary barrier which may deter young people from seeking health services. The ministry has not offered any convincing arguments for why a specific age provision is necessary.

Given the significant concerns expressed by front-line providers and public health experts, and given the serious consequences to young people's health of any restriction of access to sexual and reproductive health services and counselling, the prudent course is simply to delete the age requirement. We recommend that the committee move to amend section 8 to delete any reference to a specific age as a determinant of capacity to consent and make decisions on treatment. We support the motion to be moved in committee that section 8 be struck out and the following text substituted: "A person is presumed to be capable to consent to treatment if he or she is capable of understanding the nature, purpose and consequences of the treatment."

The current common-law practice of health care professionals being able to make judgements as to the capacity of individuals should be retained. This allows individuals to consent to medical treatment if they understand and can appreciate the nature and consequences of the treatment. Thank you.

**Mr Chiarelli:** Thank you very much for your submission. I am going to ask a question or two very similar to questions I have asked other groups. We have not seen any amendments from the government on this particular legislation, and in a lot of the sections where there have been strong objections from presenters, the government side has frequently defended the provisions and provided rationale for the provision in the legislation. I am not sure we can count on the amendments, for example, you just proposed.

On the assumption that the legislation passes as it is without any amendments, what advice do you think you would have to give a 15-year-old who thinks she may want an abortion or birth control advice? If the present legislation were passed, what would you be telling that particular individual who might come to you or an association for advice?

**Ms Jones:** It would be disastrous for such people. I would like to point out that only a very small percentage of young people who might be in that situation would be in an urban area where there would be groups like ours or clinics like the Hassle Free Clinic for birth control and venereal disease to go to. It would be a very small privileged group of people who might have access to any information we could give them as to doctors who were ignoring the legislation, or clinics that might be more accessible to them. I do not really know what the situation would look like.

**Mr Chiarelli:** Do you think you might end up almost having an underground system whereby you know the doctors, such as Dr Kaufman, who said here publicly she would ignore the legislation if it were passed—you would try to find out which doctors would ignore the legislation and refer individuals to those particular doctors?

**Ms Jones:** Yes, I assume we would be doing that. Those doctors would be swamped and they would probably be concentrated in urban areas. The effects of the legislation would be disastrous to people living in the northern or rural areas of the province.

**Mr Chiarelli:** Once again, if this legislation were passed, what advocacy role do you think you would have to undertake within the health care field to try to ameliorate your concerns with this legislation having been passed?

**Ms Jones:** We would have to find out more concretely—and I do not think it is in the legislation—what the rebuttal process involves, and we would have to do a lot of educational work to get the information out to people that they did have a way of rebutting being refused health care. I do not think any of these things are answers, though. I think a very small percentage of people would be willing to go through that process.

**Mr J. Wilson:** Just a thank you to the presenters. I note we agree on the amendment and hope the government will support that amendment or bring one similar to ours forward in the near future.

**Mr Wessenger:** I have a quick question to you about this whole age question. It has been suggested by some that if we went to the common-law position of not specifying an age, there would be a danger that many health practitioners might in effect raise the age. Do you see any danger in that?

**Ms Jones:** No, I do not think that would be a possibility at all.

**Mr Wessenger:** You do not. Thank you.

**The Vice-Chair:** I want to thank you for taking the time out of your busy schedule to appear before us today. Thank you very much.

**Ms Jones:** Thank you for listening.

1530

#### OTTAWA AD HOC COMMITTEE ON BILL 109

**The Vice-Chair:** The next group up is the Sandy Hill Community Centre. I would like to welcome you here today. Give us your names for the record and then begin when you are ready.

**Ms Muckle:** My name is Wendy Muckle. I am from Sandy Hill Community Health Centre in Ottawa. My colleague is Dr Kate Anderson, who is a physician at the Carlington Community Resource Centre, also in Ottawa. We represent a coalition of clinical staffs from the Ottawa community health centres, of which there are six.

Our community health centres are community-based organizations. We tend to take care of clients who have special kinds of health care needs. In particular, those include adolescents who are somewhat less than involved in the regular system, the proverbial street kids, and other

kinds of populations which have special needs. We felt it was important to appear in front of the committee to express our ideas around Bill 109.

**Dr Anderson:** Our committee wishes to congratulate the Ministry of Health on introducing legislation that is intended to respect a person's right to consent when capable and to provide protection which safeguards their best interests when they are incapable.

There is a need to clarify the requirements of informed consent for both health care practitioners and clients. The existing situation, where one must be 16 years of age to sign a written consent in a public hospital but not in the community, has created confusion in the minds of both practitioners and the public. To ensure that the legislation achieves its stated intent effectively, we recommend that subsections 8(1) and (2) be amended and that capacity to consent with respect to treatment be based solely on mental ability to give informed consent and that the age 16 guideline be removed from the legislation.

The first issue we would like to address is the right to confidential health care. The establishment of a specific age of consent will not clarify the confusion but will instead prevent access to health care services for adolescents and children in some circumstances. Many practitioners currently do refuse to treat adolescents without their parents' consent, despite the absence of any applicable legislative guidelines to that effect. Those who work closely with adolescents know only too well how hard it is to obtain health care for adolescents without parental involvement, even when that clearly meets the best interests of the child. It is our sincere belief that anyone seeking health care has a right to establish a confidential and trusting relationship with a practitioner and that the right to appropriate care should not be determined simply by age.

The second issue is varying capacities to consent. The problem of choosing any one age for consent to treatment is that it will always be an arbitrary measure. Many children under 16 are capable of giving informed consent while others over 16 are not. A child or adolescent may well be capable of consenting to certain treatments and procedures and not to others, depending on the complexity of factors involved in making an informed decision. The use of an arbitrary age ignores the reality of today's society, the variable rates at which adolescents mature and the complexity of medical treatment issues.

Third is the issue of access to health care services. It is our opinion that subsection 8(2), which permits the rebuttal of incapacity by persons who are less than age 16, will have an effect opposite to the intended one. It will confuse practitioners, lawyers and parents and will not encourage adolescents who are capable to exert their right to give consent. Our experience in working with adolescents indicates that an assurance of privacy and confidentiality must be given when the relationship is initiated in order to encourage them to access care and reveal all information relevant to their health needs. To work effectively with adolescents, particularly street kids, services must be hassle-free if they are to be accessible.

We ask the committee to consider the consequences of making it difficult for those under 16 years of age to consent

to their own care. It is reasonable to anticipate that we will experience a rise in unplanned teen pregnancy and sexually transmitted diseases in children under 16. In provinces like Saskatchewan, where the age of consent is 18, they are troubled by higher rates of teen pregnancy than provinces like Ontario, where no age of consent exists. Unfortunately, we may also see less reporting of abuse and detection and treatment of depression, other mental illness and addiction in the early adolescent population, despite the prevalence of these problems among that age group. The need to clarify consent issues for practitioners should not take precedence over the health needs of our children and our obligation to protect their rights.

**Ms Muckle:** I would like to address the issue of litigation. The rise in litigation against hospitals and health care providers has created a climate where there is an unwillingness to provide care where there is any likelihood of repercussion. We are just unwilling to take risks any more. It is anticipated that under the legislation as it is drafted practitioners like family physicians will be unwilling to encourage adolescents to exercise their right to consent for treatment before age 16 because they will fear repercussions from parents.

I would like to digress from our brief for just a second and tell you about what has happened recently in Ottawa-Carleton. As I am sure many of you know, we had a very serious outbreak of meningococcus disease, and six of our adolescents died from that disease. The health department went ahead and instituted a mass vaccination campaign on the advice of the region's lawyer, who based his advice on Bill 109 despite the fact it was not yet legislation. The health department required all children under the age of 16 to have their consents signed by their parents. For many adolescents who were quite capable of consenting this was a problem and for the street kids it was absolutely impossible. In fact, what happened was that the community health centres took over doing that portion of the program because we felt it was more important that the children receive the vaccination than it was to protect ourselves from any potential risk under Bill 109.

We have seen something similar in a program that we are doing with the health department on the advice of its lawyer. We are in the middle of doing a tuberculosis screening and treatment campaign for the homeless in Ottawa-Carleton because we have a serious problem with tuberculosis there. The advice of the lawyer was that we should obtain a written consent not only for a Mantoux skin test but to obtain a sputum sample and a chest X-ray. Those kinds of consents are implied consents, and even though the legislation states very clearly that is not what is needed, the interpretation of this legislation in the way it is written is going to seriously impair our ability to do our jobs and our ability to take care of people in the way we should.

I would like to move on to the determinants of health. The issue of determining an age of consent for adolescents is often considered only in the context of dealing with sexuality issues and the role of parents. We hear a lot about access to abortion, and while that is very important, health must be considered in a very broad context, as is articulated in the World Health Organization definition of health,

which this government and previous governments have espoused.

Consenting to treatment may involve much more than obtaining prescriptions, tests or having operations. Health care providers are often called upon to assist clients in accessing health, social and legal systems. Advocating on a client's behalf is an important part of health care. We provide health care in urban settings where our clients have access to many services, but we know that in reality in small towns and rural areas in the northern parts of this province where few, if any other, services exist, the local doctor may be the only source of confidential care. For an adolescent or a child to be able to seek care in confidence means a lot more than being able to get a prescription for birth control pills without having your parents know. It means being able to get accurate health information. It means being able to divulge abuse, emotional, social and legal problems. Those needs do not begin at the age of 16. They should be part of an ongoing, trusting and confidential relationship between a provider and a client of any age.

Within Canadian society access to health care is entrenched in our thinking as a right. Our health care system, which is the envy of many, is designed to promote access to care to all the residents of the province. There is no good reason to create bureaucratic obstacles to access for individuals based exclusively on their age. The very definition of informed consent requires the practitioner to determine the ability of individuals of all ages to understand the implications of the decisions they make about their health care. Ethical and professional standards of health care professionals prohibit them from providing care to individuals which is not in their best interest. The safeguards already exist to protect individuals who are not capable of making decisions which are not in their best interests and we feel there is no requirement or need for legislation or additional bureaucratic procedure.

It is our opinion that in its current form Bill 109 will do little to clarify the confusion which currently exists around an age of informed consent. We urge you not to set any particular age of consent but instead to require each practitioner to assess the capacity of the individual seeking treatment to give informed consent based on the definition as outlined in the legislation. We believe this approach will encourage the provision of care to those who are capable of consenting in all situations. It will also challenge us to consider the needs and the capacities of children and to make confidential care more accessible to those who need and want it.

Bill 109, An Act Respecting Consent to Treatment, will serve well to clarify the obligation of obtaining informed consent. For the most part it will respect the rights and needs of those seeking health care treatment. We respectfully urge the committee to consider and protect the needs and capacities of all the residents of Ontario and not deny capable individuals their right to determine their own health care needs. Thank you.

1540

**Mr Chiarelli:** Thank you very much for your brief. I want to note for other people in the room that the agenda

indicates the brief is from the Sandy Hill Community Centre. However, the brief itself, it should be noted, is presented by six community health centres in the Ottawa area, two of which are in my riding of Ottawa West. They do a wonderful service in the community and I think we should try to encourage them as much as possible. They have on-the-ground experience as well, which leads me into my first question.

Through your study and experience have you determined that there is any need to put an age restriction on consent to treatment as we have in this legislation? In other words, from your experience in the field can you understand why this provision is there?

**Dr Anderson:** From my experience I do not see a need to specify an age. As a matter of fact, I think it is very helpful to have this legislation that specifically does not designate an age because, as we mentioned in the brief, currently a lot of physicians, because of fear of litigation, are denying access to younger people, thinking there will be repercussions, not realizing they are protected under common law. No, I do not see any need to specify an age.

**Mr Chiarelli:** Dr Kaufman from the Hospital for Sick Children indicated previously, in answer to a question, that she was going to ignore the legislation if it were passed as is. I am going to ask you a specific question. Are you going to ignore it? If you do not ignore it, how do you think you will have to adjust your way of dealing with patients to accommodate this legislation?

**Dr Anderson:** I see myself being an advocate for my patient and acting in the best needs of the patient. I would try to deliver health care as best as possible within the realm of the law, but there may be situations in which the best interests of the patient clearly conflicted with the law. In that case, my ethical responsibility would probably come before my legal binding.

**Mr Chiarelli:** Do you see that conflict arising often enough to give you concern?

**Dr Anderson:** Certainly in our population, yes.

**Mr Chiarelli:** On the other point that was mentioned with respect to litigation, one of the concerns I have heard about health care costs on the part of physicians is the cost of malpractice insurance. There is the tendency for people to litigate these days and that pushes health care costs up, because physicians are probably going to want to do the extra tests and the extra examinations, which are an expense burden on the system. Do you see this legislation increasing the defensiveness of doctors in the sense of wondering what is going to happen with respect to litigation, possible court cases and how will that impact on the service you would prefer to give to your clients?

**Dr Anderson:** I see it very much increasing the fear of litigation. I think anything the government can do to decrease the barriers to care, both implicit and explicit, would really lower our costs. I do not know about the ramifications of the cost system for the advocate system and the rebuttal system, but I feel that the more the legislation can allow physicians to do their job without having lots of extra tests and manoeuvres to worry about litigation, the

better. I do see that if the bill is passed as is, it will definitely increase the fear of litigation among physicians.

**Mrs Cunningham:** I am wondering if I can have a clarification. The 16 years obviously was a contention last week and we are hearing it again this week. Could the parliamentary assistant or somebody briefly tell me why we chose age 16?

**Mr Wessenger:** I will ask counsel to answer that. I think it has to do with the fact that age 16 is presently in the Public Hospitals Act, but there may be some other reasons.

**Ms Bentivegna:** Sixteen was chosen as a balance between when a young person is usually able to live on his own and the presumption of capacity under the Substitute Decisions Act that applies to 16 and over. That was one of the reasons. With the rebutting of the presumption of over 16 and also under 16, it was felt that this would address the need to recognize the ability of competent young people to make their decisions. If they were found incapable when they demonstrated a wish to make their decision, then they would have access to the same protections as those over 16.

**Mrs Cunningham:** Could you clarify the name of the existing act that we are referring to? What act did you say?

**Ms Bentivegna:** I was saying that under the Substitute Decisions Act that applies to 16 and over. Again, the same presumption of capacity was used in the consent to treatment, but both those presumptions of capacity for 16 and over could be rebutted if the person was determined incapable. For those under 16 the presumption of incapacity could also be rebutted.

**Mrs Cunningham:** I just wondered if it was referring to legislation that we have to live with now. They are both legislation that we looking at. For instance, we choose 16 for kids to drive cars and we choose 19 to drink and we choose 21 for something else. I just thought you might have been referring to something like that. This one obviously relates to driving cars. That is the only one I can think of, and there might be something else.

**Ms Bentivegna:** There is the regulation under the Public Hospitals Act which just has 16 as an age to be able to provide consent in a public hospital. There is no rebutting there.

**Mrs Cunningham:** Okay.

**Ms Bentivegna:** Under the Mental Health Act 16 is also specified, with a rebuttal under that age.

**Mrs Cunningham:** Okay, but until this point in time the institutions that are represented here could deal with health care without having any legislation that affects the consent to treatment or the privacy of the individual around what they are doing. That is our problem. Thank you for explaining that to me. It has been helpful. All I can say is that we have already put the amendment forth and we hope the government will be listening carefully and we thank you very much for coming today.

**The Vice-Chair:** On behalf of the committee, I would like to thank you for taking the time out of your busy schedules to come and give us your presentation today.

I call forward the next presenters from the University of Toronto division of neurosurgery. Seeing as they are not

here and we are a little ahead of schedule, we will recess until 4 o'clock.

The committee recessed at 1549.

1602

WILLIAM TUCKER

MICHAEL SCHWARTZ

CHARLES TATOR

**The Chair:** I call the committee back to order. Our next presenters are from the University of Toronto division of neurosurgery. Good afternoon. Could you please identify yourselves for the record and then proceed?

**Dr Tucker:** Yes. I am William Tucker and this is Dr Michael Schwartz. Our third member, Dr Tator, has not yet arrived.

I think you all have a copy of the handout, which I have tried to keep as brief as I possibly could. Our message is fairly simple, and now having talked to some of the people who have spoken to you previously, I think you have already heard some of the points we wish to make. But perhaps we can just briefly reiterate them, and if you have any questions we will try to answer them.

We are concerned about the sections that relate to consent for research involving incompetent subjects, and I have outlined the two sections that bear on that issue. The understanding I have from the lawyers in the university is that the wording is meant to exclude that matter from consideration in the legislation. But we think it is poorly worded. Physicians in particular can interpret that as meaning the legislation does apply to the matter and prevents us from doing that kind of research.

We think the wording is potentially misleading. It may be interpreted to imply that surrogate consent for research involving incompetent subjects is dealt with by this legislation, is forbidden by it, and is illegal because of it. That would exclude Ontario medical scientists from participating even in well-regulated, ethical and scientifically meritorious research. Some of this research can only be carried out on incompetent subjects, and I will try to explain that to you in some detail.

We would like to suggest that those paragraphs, particularly that one expression, "a procedure whose primary purpose is research," which is section 15, paragraph 1, of Bill 109, should either be removed or that paragraph should be set aside from section 15, paragraphs 2 and 3, which are separate issues. It should be separated from them or rewritten to clarify the matter.

I just wanted to mention a few points about why we feel there is justification for research involving incompetent subjects in certain cases. The first thing is that often the condition that we are studying, in neurosurgery in particular, is the condition which renders the patient incompetent. In other words, they are comatose because of a bad stroke or a brain injury. By definition, competent subjects do not have the condition we wish to study. That applies to a number of other disciplines, as you can imagine: psychiatry, paediatrics and so forth.

All of the studies that are done, certainly in this university and as far as I know across this country, nowadays are

very carefully scrutinized by multidisciplinary institutional review boards. You have heard from Professor Dickens from the University of Toronto's human subjects review committee. You probably have some idea of the kind of representation those committees have and how carefully they take their responsibilities. These committees evaluate the safety, the scientific merit, the potential value to the individual participant and to society of any of these proposed clinical trials involving human subjects. Ethical aspects are very carefully scrutinized.

The other thing, perhaps from a scientific point of view, that it might be useful or comforting for you to know is that patients who are entered into the type of scientific trial we are talking about actually receive the best available treatment. In fact, there is some evidence that their treatment is improved even if the trial therapy or medication is not efficacious because there is a very high level of quality assurance; these patients are monitored very carefully. So the individual participant benefits in some cases even if the particular therapy at trial does not turn out to be efficacious.

If scientific trials of promising therapy involving incompetent subjects are precluded, physicians are able to use these therapies on compassionate grounds unscientifically. In other words, if there was a therapy that Dr Schwartz and I thought might help someone in a desperate situation and there was no scientific way to study this, we could approach the family and say: "We'd like to try this. It isn't established. This is not a scientific trial," and it would be legitimate for us to do that.

The individual would therefore be subjected to this sort of unscientific use of a new therapy. There would not be any real scientific data generated because there would not be enough numbers. There would not be proper analysis. It would not have credibility with our colleagues. So it would seem a waste when, if this is done properly with an ethical protocol, we can learn from it while at the same time trying to serve these patients.

The other very important consideration is the ethics of benefiting from information from studies of this sort if we are not participants. In other words, is it right for people in this province to benefit from this type of trial going on in other jurisdictions and in other countries if we are not contributors? I think we are expected to maintain the highest possible standard of medical care, but I do not know what the feeling would be if we were not able to contribute to maintaining that standard.

Just to finish, I have two very brief examples I would like to bring before you of protocols of the type we are talking about and the results that were achieved, just to put in perspective the kind of thing we are talking about. The first study was one that I was involved in as the University of Toronto representative. This was a Canada-wide study using a new drug that is thought to be helpful in patients who have suffered a ruptured aneurysm. These aneurysms result in blood spilling around in the base of the brain and producing a delayed phenomenon that we call spasm that impairs the blood flow. This phenomenon can be devastating. It can be fatal, and about 40% of the long-term neurological deficits in patients who survive this particular type of stroke are due to this phenomenon called spasm.

There was a very promising drug, and as much as possible had been achieved with animal experimentation but there was really no adequate animal model to study this definitively. The drug had been shown to be effective in patients who have mild haemorrhage after this type of thing. We did not know if very ill patients, who are much more susceptible to this complication, would actually benefit. So in a randomized trial with patients who were far too ill to be considered competent—they did not know where they were, what the date was, what their name was—we obtained permission from their family members. They were entered into this trial. It turned out that patients receiving this drug had a threefold greater chance of a good recovery as assessed at three months, so this outcome difference was significant from a scientific point of view.

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The results have certainly influenced treatment of patients subsequently. It is important not only for good patient care; this happens to be a very costly drug. A standard course of this costs \$1,200. It is not the kind of medication that I think you would want to pay for if it were not efficacious.

There was another study that was actually carried out entirely in this university several years ago. Dr Tator and Dr Schwartz were principal investigators in that study, which was to assess the benefit of pentobarbital, a drug that was thought to be of some benefit in controlling high pressure in the head after a very serious head injury. All of these patients, by definition, were unconscious and therefore incompetent. The treatment is very costly and expensive because it renders the patients even more deeply unconscious and dependent on life support systems for a prolonged period of time, so if it is not efficacious, it should not be used. In addition to that, there were some potential side-effects of the treatment, so it certainly should not be used if it is not of benefit.

In this study it was learned that particularly in one subgroup of patients, this particular treatment was not effective, and in fact the patients had a higher mortality and a worse outcome than patients treated with the more conventional therapy available. That has certainly influenced how we treat these patients since that time. I do not think that kind of information could have been derived by any other means.

Mike, did you want to add anything about that study?

**Dr Schwartz:** Just to say that this was research done at the University of Toronto and in fact that publication was the first in the world on this particular topic—not exactly the first in the world on the topic, but the first prospective randomized trial, the first carefully done study that could arrive at the sort of information we wanted to have. Our results were subsequently confirmed by other universities. We discovered that, as Bill Tucker said, not only was the drug not helpful for those patients who did not require a blood clot to be removed from inside the head, but it was actually harmful. If that study had not been done, we would likely still be treating those patients with pentobarbital today and causing them harm. So it is very important that this type of research be carried out.

**Dr Tucker:** That is the end of our formal presentation. Now that Dr Tator has joined us, we will try to answer any questions you might have.

**The Chair:** Thank you. Questions or comments? Mr Chiarelli.

**Mr Chiarelli:** It is more of comment than a question. Dr Lowy and several other very qualified people have been before this committee to argue the same points you have presented here today. I can only say that we are hopeful that the government has listened and will bring in some amendments to address this particular concern. If the government does not do so, I assure you that at least the Liberal members of the committee will introduce amendments to address your concerns. At that time, whenever we may be considering clause-by-clause, we may be getting back to you for some assistance in technically drafting the amendments.

**Mr J. Wilson:** Thank you, distinguished guests, for taking time out to drive this point home to the committee. Really, my comments reflect exactly what Mr Chiarelli has already said. I am always at a disadvantage because the Liberals always go first, but we too will be working with the Liberals to bring forward amendments if the government does not see fit to do so in this case.

**Mrs Cunningham:** Perhaps I could ask, when the government members have a chance for their questions, if they could answer a question from myself. I am interested in Bill 109, section 15. I am wondering why it was included at all. I would appreciate the rationale, since we are on that section and I did not have the opportunity to hear it before.

**The Chair:** Would somebody like to respond right away?

**Mr Wessinger:** I will have a comment when my time comes up that will deal with that issue.

**Ms Carter:** I would like clarification on one of the points that you made. You said that sometimes a patient can benefit even if the experimental treatment does not happen to work. Surely that must mean that patients receiving that kind of experimental treatment must be getting better attention overall than if they were not? The care givers in that facility must be, as it were, more concerned, and the patients must be somehow getting superior care.

**Dr Tucker:** That is not deliberate, but is a well-documented truth that happens. The level of monitoring, the quality assurance is better because they are in a study protocol. We certainly do not neglect the other patients by choice, but—let's say the treatment has no effect: no positive effect, but no harmful effect. We know those patients are probably somewhat better off because they have been in such a protocol.

**Mr Wessinger:** Thank you for your presentation. I have a question. We had here last week, I guess it was, Professor Dickens from the University of Toronto. He is an expert on the law with respect to the matter of treatment and research, and he indicated to us that the existing common law sets out the situation where you can say research has a therapeutic purpose in that if it is anticipated that it may be of benefit to the particular individuals, it may be performed on incapacitated people. He also outlined the situation that

research which had no possible or no likely advantage for the individual, so-called non-therapeutic research, was not legal under the existing common law.

When I look at these two examples here, examples 1 and 2, it would appear to me that example 1 might fall under the category of therapeutic research and therefore might be legal, but example 2 would appear to fall under the category of non-therapeutic research and therefore would not be legal under the existing common law. I wonder if you might comment on that.

**Dr Tucker:** No, they were both modalities of treatment that were felt to be possibly beneficial, thought to be therapeutic. In fact, in the second example that you refer to, there was considerable sporadic reporting that this was a beneficial treatment in humans and certainly a lot of animal work that supported that treatment, so we thought it might be beneficial. But because there was this potential downside of lowering the blood pressure and because it was a very costly treatment, we thought we had better find out for certain.

In both those things and in virtually all the studies we are talking about in this context, there is potential benefit. We are usually trying a therapy or an agent that we expect and hope will be beneficial, but we have not satisfactorily proven it scientifically.

**Mr Wessenger:** All right. I appreciate your clarification on that.

**Dr Schwartz:** May I speak to that? It is just to say that that particular treatment, which in effect is a 10-day general anaesthetic, was proposed very enthusiastically by numerous prominent physicians in both the United States and Canada, and we believed at the outset that it might very well be helpful. In fact, we had given it in just the way Bill Tucker described, as compassionate or last-ditch treatment for people who were not benefiting from the standard type of care, and yet it was not known for sure whether it helped or was harmful. It was by doing the study in a scientific way that we discovered that for one class of

patients it was in fact harmful. It did not start out intended as research without benefit; we expected that there would be benefit.

**Mr Wessenger:** You expected that it would be beneficial to the patients. Thank you for clarifying that.

The other thing I would like to indicate to you is that clearly the intention of this legislation is not to in any way affect the existing law with respect to the matter of research, and if clarification is needed, hopefully that clarification will be made. Thank you.

**The Chair:** On behalf of the committee, I would like to thank you, Dr Schwartz, Dr Tucker and Dr Tator, for coming and giving your presentation this afternoon.

**Dr Tucker:** Thank you for the opportunity.

**The Chair:** Mr Poirier.

**Mr Poirier:** I would just like to inform my colleagues, especially in government, that the Liberal Party has just issued a press release, thanks to a brown envelope under the door, where we have the complete list of the legislative priority-setting exercise for the government in power. You will be glad to know that the advocacy bill is number eight in the list of priorities and that the number one priority is the Ontario Labour Relations Act amendments. It says "controversial overall of act, urgency to not have debate on this item carry over into 1993." This for your information, sir. Number eight priority, our bill.

**Mrs Cunningham:** Mr Chairman, I have an announcement. Canada won the hockey game by shootout. I thought you would like to know that.

**The Chair:** Good. Mr Poirier, would you like to table that document?

**Mr Poirier:** It is a public document. You will be able to get it for your perusal later on tonight.

**The Chair:** Thank you very much for that information.

The committee adjourned at 1621.

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## Assemblée législative de l'Ontario

Première intersession, 35<sup>e</sup> législature

# Official Report of Debates (Hansard)

Wednesday 19 February 1992

# Journal des débats (Hansard)

Le mercredi 19 février 1992

## Standing committee on administration of justice

Advocacy Act, 1991,  
and companion legislation

## Comité permanent de l'administration de la justice

Loi de 1991 sur l'intervention  
et les projets de loi  
qui l'accompagnent



Chair: Mike Cooper  
Clerk: Lisa Freedman

Président : Mike Cooper  
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# LEGISLATIVE ASSEMBLY OF ONTARIO

## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

Wednesday 19 February 1992

The committee met at 1006 in committee room 1.

### ADVOCACY ACT, 1991, AND COMPANION LEGISLATION

#### LOI DE 1991 SUR L'INTERVENTION ET LES PROJETS DE LOI QUI L'ACCOMPAGNENT

Resuming consideration of Bill 7, An Act to amend the Powers of Attorney Act; Bill 8, An Act respecting Natural Death; Bill 74, An Act respecting the Provision of Advocacy Services to Vulnerable Persons / Projet de loi 74, Loi concernant la prestation de services d'intervenants en faveur des personnes vulnérables; Bill 108, An Act to provide for the making of Decisions on behalf of Adults concerning the Management of their Property and concerning their Personal Care / Projet de loi 108, Loi prévoyant la prise de décisions au nom d'adultes en ce qui concerne la gestion de leurs biens et le soin de leur personne; Bill 109, An Act respecting Consent to Treatment / Projet de loi 109, Loi concernant le consentement au traitement; and Bill 110, An Act to amend certain Statutes of Ontario consequent upon the enactment of the Consent to Treatment Act, 1991 and the Substitute Decisions Act, 1991 / Projet de loi 110, Loi modifiant certaines lois de l'Ontario par suite de l'adoption de la Loi de 1991 sur le consentement au traitement et de la Loi de 1991 sur la prise de décisions au nom d'autrui.

#### ONTARIO ASSOCIATION OF MEDICAL DIRECTORS IN HOMES FOR SENIOR CITIZENS

**The Chair:** I would like to call forward our first presenter, from the Ontario Association of Medical Directors in Homes for Senior Citizens. Good morning. Just a reminder that you have a half-hour for your presentation. We would appreciate if you would limit your remarks to 15 minutes and allow time for members to ask questions or make comments.

**Dr Ellyatt:** I will do the best I can.

**The Chair:** As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Dr Ellyatt:** I am Dr William G. Ellyatt. I am medical director of the Dearness Home in London and I am a member of the board of directors of the Ontario Association of Medical Directors in Homes for Senior Citizens.

Several brief comments about Bill 108, the Substitute Decisions Act: First of all, our association agrees that there is a need for this act in some circumstances, but we are very concerned, both as physicians and as medical directors in homes for the aged, about the act and its consequences for some of the people we care for, given the very large number of Alzheimer's victims presently residing in homes for the aged in the province.

Most people in Ontario will not bother to appoint an attorney for personal care ahead of the time of need.

Consequently the courts are going to be needed to appoint such attorneys, and there will be a large number of people needed both to act as attorneys and as advocates, particularly the latter.

The first question we have is, who is going to pay the advocates? The public trustee's office will probably have to expand or be swamped with decisions regarding care for Alzheimer's victims alone. I would remind you that it has been forecast that at some time in the foreseeable future, probably in the next 25 years, the increase in the number of Alzheimer's victims alone could bankrupt the entire North American health care system.

How are the advocates going to be contacted out of hours? Who will act if the designated advocate or attorney is on vacation or incapacitated or otherwise unavailable? It is a big question in our minds. Unfortunately, crises in care do not often occur during so-called office hours and all too often they will not wait until office hours begin.

With regard to sections 44 and 45, how is it that a person 16 years of age can act as an attorney for personal care but cannot vote? I think this is something that the law should take a look at.

The process of appointment of an attorney for personal care is rather cumbersome and time-consuming as it is outlined in the proposed act. It will likely be very expensive. It will likely involve the services of at least two lawyers plus court time and all the costs that go with that. Who pays for all the legal time? And note, please, that OHIP will not pay for third-party medical costs such as the preparation of a report by an attending physician. Are these costs going to be billable to the person being assessed for competency, who may not be able to comprehend what he is being billed for and at the same time may not have the funds to pay for such a billing?

Under section 56, what is going to happen to research and to treatment for various psychoses, dementias and in particular Alzheimer's dementia if a promising treatment for these particular diseases cannot be tried out?

There are few psychotics and even fewer Alzheimer's victims who will consent to try a new drug, no matter how promising that particular drug might be. Section 59 offers still further work and further cost to the public trustee's office in such circumstances.

Under subsection 59(5), the explanation by an advocate to serve an Alzheimer's victim is an exercise in futility. The person may be able to comprehend at this moment, but not five minutes from now, just exactly what is going on. In my experience persons in some advanced cases do not know what day of the week it is, whether they are existing on one day of the week, where they are etc. To put it as was said to me at one time, they often do not know whether they are a horse or a foot. It is often like trying to talk to a blank wall.

Under section 63, what I have just read out applies equally vis-à-vis the guardian's duties.

Under subsection 63(7), it would be very helpful if the law could ever define what is known as a restraint. This has never been defined in medical-legal terms. It would be helpful if the Attorney General's office could define it. Is the use of two bedrails a restraint? How about a brightly coloured jacket to identify an Alzheimer's victim who wanders? How about a seatbelt on a wheelchair or even a table across a geri-chair? These are important things to know. Can we put a safety belt on a person in a wheelchair? We have to in an automobile.

Under section 64, referring to the annual report by the attorney for personal care and the guardian, what will be the penalty for not completing the annual report? Who is going to monitor these particular reports and read them well? How much extra staff is going to be required for that particular item? I would point out to you that in the municipal home over which I am medical director there are currently over 300 people who may require such a report and the number is growing annually. Under the current outline of the act the administrator of the home and the people who work for the home are excluded from being either attorneys or guardians.

The procedure under the guardianship section is just as detailed and just as cumbersome as that under the attorney for personal care and, I would point out to you, a further added heavy court cost.

Under subsection 72(4), the time limit for a medical assessment is set at six months. This works well for a person who has a chronic, ongoing mental illness. But the need often is right now, not in six months, so what do you do if the person who has an acute dementia needs treatment? People change rapidly, sometimes depending on trauma, health medications etc. What holds for this moment may not hold for three months from now. The time limit seems rather excessive.

Furthermore, notation is made that there are two assessors necessary: one a medical doctor and another an independent person. Who pays the other assessor, even if OHIP would pay the doctor who is filling out the report?

Under section 74, again about the advocate, if the person will not listen to the advocate then it is back to the courts. I might point out that the civil courts already seem to have a backlog of multiple months. Will the courts be empowered to sit at night, late afternoon or early morning at a time when necessity dictates that they should? I know from personal experience that sometimes courts will ask for detailed reports on less than 48 hours' notice. How can these be turned out? It takes a reasonable length of time to make an examination, dictate a report and have it typed, copied, distributed etc. When we are dealing with someone's long-term mental health and physical needs, 48 hours is often not enough time to assemble all the data necessary.

The OAMDHSC is most concerned about the position in which attending physicians will be placed if this act is passed into legislation in its current form. Hospitals, homes for the aged, nursing homes and so forth are similarly concerned. If a person who has a guardian or an attorney refuses to be bathed, groomed, toileted and so

forth, will it take a court order to be able to proceed under such circumstances?

It certainly will not be a surprise if emergency surgery is needed, because it is going to take time to come to a decision as to whether or not emergency surgery is needed. Two doctors can sign for that, of course, but elective surgery is another major problem. The same thing holds for illnesses that would require such things as oxygen, intravenous therapy, nasogastric tubes and even catheters. The main concern of our group is: What happens on a day-to-day basis? How long will it take to get the informed consent under rather difficult circumstances?

I would be pleased to try to answer any questions you might have.

**Mr Poirier:** Would you be ready to provide a list of detailed amendments you would like brought forward that would address your concerns? It is relatively easy for us to understand how it can affect you in your everyday life, but maybe you could sit down with your colleagues and specifically point out and provide us with some material as to what you would like to see so that your everyday life and your mandate, where you work, are not adversely affected in the way you perceive that the current bill or bills, as they go forward, will cause you more problems than bring solutions. Could you comment on that? Would it be possible for you to do? Do you feel comfortable with that?

**Dr Ellyatt:** Not being a lawyer, it is a little difficult.

**Mr Poirier:** That is an advantage.

**Dr Ellyatt:** Perhaps we would not come up with a few pages of legalese that would be hard to interpret, but—

**Mr Poirier:** That is right. We would understand what you are saying.

**Dr Ellyatt:** What sort of time limit would you be placing on us?

**Mr Poirier:** In the next couple of weeks. It is the number eight priority, as per the list that was leaked yesterday, for the government legislative process. It being number eight, at the rate they are working you have lots of time. I would not want to give you an exact figure, but at your earliest convenience would be appreciated.

**Dr Ellyatt:** We can attempt it.

**Mr Poirier:** I think it is important.

**Dr Ellyatt:** I have not seen the list. I did not get a chance to read the paper this morning before leaving home.

**Mr Poirier:** Fair enough. I can provide you a copy. Even the government members could now provide you a copy, because we gave some copies yesterday for them to see, you see. It is the number eight priority and it is not going to be tomorrow morning, but I think it would be important if you could sit down and look in detail at the bills and identify the points that you feel are going to cause some particular problems in your everyday mandate. If you could specifically identify them and make some suggestions, we will seriously consider them.

Do not hesitate to give a copy of that to the government members. They like to get copies of what amendments they should bring forward. If the government

members want to bring forward the amendments, we will be most grateful.

**Dr Ellyatt:** To whom should those be addressed?

**Mr Poirier:** You can address them to Ms Freedman, the clerk for this committee. This way at least it will be non-partisan when we make certain that all of us get some copies so that we can have a look at your suggestions for amendments. I think that is very important because you think you are going to be affected in your mandate by these proposed bills as they now stand.

I think it is important that you take the time to have a good look at them. Do not worry about the legalese. Bring it forward and we can operate and make sure that your concerns are addressed as much as possible to make these bills—because they are going to come out. This is a majority government. But we will try our best to make sure the proposed amendments you would want to see in there so you can do the mandate you and your colleagues care to do will be brought forward as much as possible.

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**Dr Ellyatt:** If we could come up with some suggestions that make the bill at least workable.

**Mr Poirier:** That is exactly what I am asking you.

**Dr Ellyatt:** Because as we see it now, it is totally unworkable and cumbersome.

**Mr Poirier:** I could not have said it better myself. See? You are not a lawyer and your message and your answers are very clear. You said in 25 words or less what I have been trying to tell you for five minutes.

**Mr J. Wilson:** Sir, I appreciate the comments you have made. Many of the points you brought forward have been brought to our attention previously, but it is necessary in this day and age to drive the points home. I did take some notes, and I am curious. One of your first comments was that you note that a person 16 years of age is of age to become an attorney for personal care. Did you have some thoughts on what an appropriate age would be?

**Dr Ellyatt:** I grant you there are some who have a very elderly head on very young shoulders at age 16, but I have seen a lot of people who really did not have enough insight into a situation or what is best for a relative to be able to act even at age 18. However, my feeling would be that even at voting age a person probably could act with more knowledge aforehand than a 16-year-old possibly could. As I say, there are 16-year-olds who are wise beyond their years, I will grant you that, but I would guess that very few of them would want to take on the responsibility of second-guessing a person's future.

**Mr J. Wilson:** I appreciate that. I think that is all for now, Mr Chairman.

**Mr Morrow:** First of all, Dr Ellyatt, I would just like to thank you for taking the time out of your busy schedule to appear before us, and I want to pick up on something Mr Poirier was talking about. As a government member I feel it is really important that you give us your proposed amendments so we can have a look at them. I would not worry about them being too legal. We have legal counsel who can reword them and things like that. That is what

these public hearings are all about: so we can hear witnesses and we can make, hopefully, the proper amendments you and the public want. I just wanted to make that comment.

**Mr Winninger:** I too would like to welcome you here today. I know the facility you run very well since it is right across the street from my own constituency office in London. I have toured it. I know you do a lot of good work with Alzheimer's patients, and that is why I can understand the concerns you have shared with us today.

I do not know if it is any reassurance to you, but we have had some clarification on section 15 of the Consent to Treatment Act indicating that that section, as far as research on people who lack capacity is concerned, is really status quo neutral. It does not change the existing arrangements with regard to consent to research.

I would also suggest to you that our guardianship procedure, however cumbersome you may find it under Bill 108, does address the need you have expressed so well of Alzheimer's patients who lapse in and out of capacity to have someone who does have a more permanent form of guardianship who can consent to treatment on behalf of people who lapse in and out of consent. I think that might prove of some comfort to you ultimately.

You have covered a number of different technical points and I too would like to see them presented in writing in whatever form so we can consider those suggestions when we move to clause-by-clause.

**Ms Carter:** You were not specifically targeting the Advocacy Act, Bill 74, but the concept of an advocate that is delineated there is consistent, I guess, throughout the three bills. Now, you said if a person does not listen to an advocate, then it is back to the court. This seems to suggest that maybe you have misunderstood what the role of the advocate is supposed to be. The advocate is to listen to the patient or the vulnerable person and not the other way around. It is not the advocate's job to make any kind of decision for that person.

**Dr Ellyatt:** It was my conception that the advocate was at least to explain to the individual what is happening, why it is happening, and then to receive from the individual some sort of consent or refusal of consent. Certainly in the original bill, all 270 pages of it, it was rather clear that when a person had the problem explained to him, if he said "no way," then it was back to the court for the advocate to be told to go out and see the individual and explain it again.

**Ms Carter:** Maybe we could ask counsel to elaborate on this point.

**Ms Spinks:** It may be an issue that Mr Fram wants to address since I think we are talking about Bill 108, but as I understand it, the advocate is to give the person the explanation if he has been assessed by the assessor as incapable and then give a report—if we are talking about statutory guardianship—as to whether the person objects to the guardianship. That is a very simple procedure. Thereafter the advocate is out of the picture. I think the presenter is perhaps correct in that if the individual does object, then the role is for the individual who would like to obtain guardianship for that person to apply to the court.

**The Chair:** Dr Ellyatt, on behalf of the committee I would like to thank you for taking time out this morning and giving us your presentation.

#### ONTARIO NURSING HOME ASSOCIATION

**The Chair:** I would like to call forward our next presenters, from the Ontario Nursing Home Association. I would like to remind you that you have half an hour for your presentation. We would appreciate it if you would limit it to 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Ms Peppler:** Thank you for giving us the opportunity to discuss our concerns about the proposed advocacy system with you today. Three of us will be presenting the Ontario Nursing Home Association's concerns. Fran Bouchard, at the end, is a nursing home administrator and has much experience with the day-to-day issues regarding consent to treatment and competency. Next to me is Deborah Wall-Armstrong. She is a lawyer and nursing home owner and she too has much experience with these issues from both a legal perspective and an owner's perspective. I am Carla Peppler. I am director of resident care at the Ontario Nursing Home Association and I help members with these issues on a daily basis.

We have divided our presentation into two parts. The first part will be a review of the current resident profile and a discussion of the future profile in light of the redirection of long-term care. Second, we will highlight some of the major concerns outlined in our brief.

Let me start by describing our current resident population. Seventy-five per cent of our residents today are severely to moderately cognitively impaired. This means they have difficulty making decisions. They are not oriented to time, place, person or event. This means they often do not know who they are, where they are or what time of day or season it is. They are unable to form judgements and they do not know how to evaluate risk. So we see behaviours such as eating plants, eating napkins, wandering away from the facility, smoking unsafely, those kinds of things. They are unable to follow instructions. In fact, even simple tasks such as brushing their teeth become very difficult for them. What staff have to do with something like that is put the toothbrush in their hands, give them the toothpaste and tell them to put the toothpaste on the toothbrush. You then have to direct them to put the toothbrush under the water, put the toothbrush in their mouths and then show them almost how to brush their teeth, and you have to do this every time they need to brush their teeth. Their memory is often impaired and they are not capable of learning new skills or information.

Fifty-four per cent of our residents have behaviour problems such as aggression, wandering, hoarding, screaming, that kind of thing. Often these behaviours impact on the quality of life of other residents. For example, their property is taken, their environment is noisy from the constant screaming or moaning, and unfortunately, sometimes they are victims of an aggressive act by another resident.

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Eight per cent of our residents are unresponsive in that they are unable to communicate at all. This could be because of a stroke or they could be semicomatose. What this means, however, is that staff are unable to confirm that resident's wishes or preferences.

Sixty per cent of residents have difficulty communicating, either because of a psychosis or an aphasia, which is a type of problem you get after you have a stroke. They may have a language barrier or they may be unable to transmit or understand communications because of diseases like Alzheimer's. For example, with Alzheimer's disease they often hear the words you are saying but they are not able to interpret them and put a meaning to those words.

Last, 20% of our residents have no family or next of kin, and these residents require even more staff time for social, family-type support.

With the proposed changes resulting from the redirection in long-term care we are going to see an increase in the number and severity of cognitive impairments. This means theoretically that 100% of nursing home residents will require substitute decision-makers for personal care. More residents are going to have behaviour problems, probably a lot more aggression, and these behaviours are going to impact on the rights of other residents. We can foresee an increase in advocacy services to determine which residents' rights supersede.

More residents are going to be bedridden, thus increasing the number and severity of medical conditions and problems such as pneumonia, skin ulcers, urinary tract infections, even choking. This means residents will be sicker and require more medical interventions, possibly on a daily or even hourly basis.

The residents' length of stay is going to decrease as residents are going to be coming into our facilities at a much sicker and frailer level. This in turn will result in an increase in the number of admissions.

We will probably see even less family involvement and support. In fact, what we are starting to see now is two generations of the same family coming into our facilities. You will have mom at 96 and daughter at 75.

In general, you are going to see care levels increasing as the residents' need for care from staff becomes quite total. These changes in our resident profile will affect who will require the services of an advocate and who will require substitute decision-makers. Currently there are 30,000 residents in Ontario nursing homes. As the majority of residents are currently cognitively impaired, the demands on the proposed system will be great. Remember that the future resident will be even more impaired and the number of long-term care facility admissions is going to increase; thus the demands on the proposed system will be even greater.

ONHA supports the concept of the proposed bills, but we are concerned that the hoped-for achievements are too ambitious for the legislation. The package, devised with the best intentions, is attempting to do too much too quickly. As a result, expectations will swell far beyond reach and the outcome will be less than desirable.

Critical to the success of the package is the availability of supports before the provisions are enacted and small-scale testing of the concepts in operation.

We are worried that our residents will not receive safe and timely care following the enactment of these bills. Already our health care staff are paranoid about meeting legislative requirements. These bills will further complicate care delivery and take staff further away from the resident side. Staff are already concerned that they are going to be unable to meet these requirements. Some of their concerns are as follows.

The first involves the definition of "treatment." In Bill 109 treatment requiring consent is broadly defined, involving nursing care and, by implication, any other type of personal care. Essentially, you have everything from blood tests to analgesic rubs to surgical procedures, even nail-clipping. Essentially, all procedures and care services provided in nursing homes fall under the proposed definition.

Residents in nursing homes are no longer the medically stable people they were years ago. We now have residents who have multisystem problems. That means they have problems with their heart, they have diabetes, they have arthritis, they have respiratory problems, and unfortunately many have cognitive impairments on top of all of that. These kinds of problems require frequent observations and monitoring. We now have residents such as diabetic residents who are so unstable they have insulin dose changes every day and other changes to their medical and nursing regimes.

As you can see, the resident treatment plans can and do change often. Would these changes need to have substitute decision-makers' approval before they could be given? It is important to note that health status in an elderly compromised resident can change extremely quickly. Medical intervention must occur quickly to prevent a medical crisis. Further, the time and manpower necessary to obtain these consents would go beyond the capacity of nursing home personnel. A resident's access to timely quality care could be jeopardized because of the requirement.

ONHA recommends that consideration be given to a blanket consent for the plan of care and to redefine treatment in requiring the consent of a substitute decision-maker to those procedures that are invasive or that do not happen on a regular basis.

Our second concern is the need for clear guidelines on evaluating competency. All three bills depend on the determination of competency before the respective procedures can be carried out. What is missing from this package is a bill defining competency and a process for assessment, including who can do that assessment. It is imperative that this piece of legislation come first. Determining competency is critical to the success of the implementation of the other three bills.

A third concern is with the definition of "emergency." In Bill 109 the definition of emergency could be problematic for many elderly persons. A medical emergency to an older person may present quite differently than it does for you or me. An elderly person is similar in frailty to the premature baby or newborn in the need for quick intervention to avoid a crisis. For example, an infection in an older person must be treated immediately, as an older person, like a

newborn, can become septic or have a full-body infection in a relatively quick period of time. Further, emergency care may become less timely and effective if health care workers are worried about potential liability. A definition of emergency needs to be developed that is not based on time, but rather the severity of the condition and the consequences of withholding care.

Bills 108 and 109 hold the professional liable for breaches of procedure. In fairness to them, there must be an educational program to help them understand their new role and the implications for their practice. As well, they must receive protection from disciplinary hearings when they uphold the requirements of the legislation.

Fran Bouchard will now review our concerns with facility admissions.

**Ms Bouchard:** Because the majority of residents entering long-term care facilities have some degree of cognitive impairment, the number of competency assessments, designations of powers of attorney and substitute decision-makers will also increase substantially. To facilitate safe, effective care upon admission, in reality we suggest that the following are a must: Competency legislation which defines competency and outlines an assessment process must be enacted before the bills are implemented; the need for substitute decision-makers should be made prior to long-term care admission; and a blanket consent for daily plan of care, as well as a pre-validated living will. Such a will would be drawn up when the individual was competent, detailing that person's wishes for personal and medical interventions in times of incompetency.

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**Ms Wall-Armstrong:** I am going to deal with the need to clarify the role of the health practitioner and where the advocate steps in. Health practitioners are committed to providing care, but the package of legislation can be expected to take time away from providing care to satisfy the required procedures. We question whether it is really appropriate for the health care provider to be responsible to fulfil many of the requirements of the bills, especially when the purpose of the legislation is to protect the individual from undesired care.

For example, finding the ideal substitute decision-maker in section 16 of Bill 109 is the responsibility of the health practitioner. We question the appropriateness of such a requirement. This legislation is going to require a health practitioner to start making decisions for people that to date have been made by judges trained in weighing evidence and seeking out information. Health practitioners have not been trained in their education to do that type of work, they generally have no interest in doing that type of work or time for it, and they will want to know who is going to compensate them for their efforts. Judges get paid for their work.

In nursing homes we already have a problem in getting medical doctors to take over care of residents in the homes because of the existing paperwork and forms. Some homes do not have an advisory physician because no one wants the paperwork hassle that goes with it. Without changes to the acts, that situation is going to get much worse. Our

in-house staff are currently under pressure to find enough time to do hands-on work with residents as it is. Where will the time come from to do this unless the staff reduce their hands-on?

Without a quick test built into the act for who is a partner to an individual or how far does the staff go to find the patient's best representative, the problem of wasted valuable hands-on time is only going to get worse. We suggest that these responsibilities are better left to a trained advocate, who will not have to reinvent the wheel in trying to make these decisions.

I want to deal with the other part of where the advocate steps in, because based on the resident population and the number and types of consents required, all long-term facilities will require onsite advocates, at a cost far exceeding those being estimated. Without significant change, the dollar cost estimated for implementation is at very best described as naïve. To make the bills workable, whom advocates serve—the individual or the advocate—must be defined more clearly, as do the types of decisions related to consent and substitute guardianship. From a practical perspective, clear guidelines are required outlining whom, when and how to call an advocate.

The ONHA is recommending that a pilot program be implemented to test the proposed advocacy model. In this way the model can be evaluated and adjustments can be made before widespread implementation. Pilot projects are being used successfully in other areas, like land registry reform and court case management, to work out the kinks in those legislations, and you only have to look at fiascos created by the province-wide implementation of legislation like support and custody order enforcement and rent review in 1985, where initial cases took years to be dealt with, resulting in public frustration and disdain for the legislative procedure. I am told there are similar problems with the human rights legislation. These were doomed by a lack of preparation, funding and an awareness of the enormity of the work to be undertaken. The net result is that vulnerable people we want to help will be put at more risk. We all want to see legislation passed that will be functional, not dysfunctional.

That actually ends our oral presentation, except for your questions. I would like to point out that in our written presentation we have had circulated there are many more concerns. We have touched on about six of them. There are approximately 15 in our paper. Thank you.

**Mr Chiarelli:** Thank you very much for your well-thought-out brief. It has a number of themes we have heard from other presenters. We heard yesterday from Dr Kaufman, from the Toronto Hospital for Sick Children, that if this legislation were passed as is, he personally as a professional would ignore it. He had an associate, also a doctor from the same hospital, who said that if this legislation were passed as is, it would create chaos in the hospital setting.

We heard last week from Dan Ferguson, who is a lawyer experienced in the health care field, basically saying that this legislation would also create chaos. We had a physician here yesterday from the Carlington Community Health Centre in Ottawa who said she could foresee a lot of conflicts between her ethics and standards as a doctor and this

particular legislation, and in circumstances of conflict she would certainly choose to ignore the legislation.

I am going to ask you to describe to members of the committee what you think, collectively or individually, would happen in your area of care if this legislation were passed as is and as contemplated—because we have no idea what amendments may or may not be forthcoming—with particular attention to what you described as narrowing the scope of the definition of treatment. But as it is now, what will happen in nursing homes across the province with this legislation in place?

**Ms Bouchard:** Being a front-line worker, I can tell you that it certainly would be a tremendous problem for us. The advisory physician we currently have would have a very difficult time with that. In our present situation we have 50 seniors who are all cognitively impaired, and also a population of 60 developmentally delayed adults, the majority of whom have no contact with their families, and 13 of whom have absolutely no next of kin.

We have had a situation in the past 18 months where one of these residents became terminally ill. Who was going to decide what kind of treatment was going to be provided for this person—palliative care, possible surgery, pain management, all those things? It was a very tedious process. We had to appear twice before the ethics committee of our local hospital, and we had to involve the office of the public trustee. A lot of time was spent between September and December, and while someone was trying to make a decision, we still had to provide care for this person. So it really does put everyone at risk—the resident, the physician, the office of the public trustee, myself—I have a licence—the owners of the nursing home, and above all, the resident.

**Ms Wall-Armstrong:** The other part of that is, in talking with our advisory physician—and our difficulty with our particular advisory physician may be the fact that he is both a lawyer and a medical doctor—he read the package of legislation and said, “I can’t even do a physical on any of the people in this home until I have consent forms,” and he is paranoid about touching anybody or doing any work.

We have enough problems right now just trying to get doctors to come in and deal with the patients in the home. We are afraid we will not be able to get anybody to come and take care of these people because they will be afraid of the liabilities involved with the legislation. He is at least able to read the legislation. Maybe he can read too much of it.

When I check with others in the medical community, any time you talk about additional paperwork or any kind of involvement in government legislation they back off. You only have to look at the increase in paperwork in Workers’ Compensation Board forms and see how many doctors do not want to touch a WCB case. This legislation imposes even more problems or concerns for them. I just see it as a major problem.

**Mr Chiarelli:** I was particularly interested in your comments that you support the concept of this legislation. You would like to see legislation with these particular principles implemented. We have had a number of people come before the committee and say: “We’ve been waiting for a long time for this type of legislation. Let’s get it in

place and we can refine it later." In fact, yesterday we had one presenter suggest, "Implement this legislation and get a committee to review it three years down the road." Do you think the imperative to have this legislation in place outweighs the serious concerns, and some people have described the chaos, that might be created if it were in place as is?

**Ms Wall-Armstrong:** I personally think that if we have waited this long we can wait a little longer to implement something that is actually going to work. I am really concerned that we are going to make the situation worse and worse for many years before we can straighten it out. I would rather see some of the suggestions that we are looking at here about the definition of competency, about dealing with a model of it in our work, so that we have an opportunity to work those kinks out.

We do not want to have to continue in the circumstances we had with the one resident in our home already. It took months, and even with everybody trying to cooperate, the individual essentially went on for months without getting what I would consider immediate care. We want that to improve.

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My concern is, you pass this legislation right now, we could be a year, we could never get anything for two or three years for some people. So as much as you want to have it passed, if you are going to do that, at least do it on a limited scale as a pilot project so that the concerns people are looking at can be addressed. Then if everything is working fine, you can expand it. You will also have trained people in place to answer a lot of the questions, and you will deal with a lot of the frustration.

I think you are going to end up with legislation that has been passed but is going to get swamped by the demands and is going to end up, as I say, like it ended up in rent review, where people would file an application the first year and it took four or five years before they could even have their case heard. People cannot wait four or five years for this kind of help. They need to have some more immediate intervention, so if you are going to make it worse, do not pass the legislation. Leave us at least with what we have in place, it only takes us three or four months on it. But if you pass this and it takes us a year, our people are going to be worse off.

**Ms Peppler:** One thing you have to remember is, nursing homes do not have the luxury of ignoring legislation. We are heavily inspected, and that process is there to somewhat ensure that we follow legislation, so what is going to happen is, our staff will spend the time meeting these requirements, doing the paperwork and spending less time at the residents' bedsides.

**Mr J. Wilson:** Thank you very much for your presentation. I think you have made some excellent suggestions, and I am very supportive, as I think my Liberal colleagues are—and we do not often agree on too many things—of the pilot project idea. Your examples of legislation passed five, six years ago are right on; it should have been handled through pilot projects at that time. I think we are in agreement on that, despite the fact that it was their government that did it.

I will not get into that, because I do not want to be partisan, except to point out that the rush here—and I will give a plug to Lyn McLeod, the Liberal leader, who yesterday, of course, got a brown envelope indicating that this is number eight on the hit parade for the NDP and there is a rush. It says right in it that there was a commitment made to the province's disabled community, and they are in a real rush to ensure that the commitment is fulfilled in terms of this legislation being enacted as soon as possible.

I have one specific question, though, on one of your recommendations. I am worried about the level of bureaucracy already envisioned in this legislation and about the paperwork, and you have given a very good example. I know from my own riding that there is a reluctance by physicians, the one example you gave, to go into nursing homes and serve nursing home clients.

You mentioned in one of your recommendations that the Advocacy Commission really should be monitored by a provincial board. What are your concerns or your fears there?

**Ms Wall-Armstrong:** I think it is the accountability of the Advocacy Commission, and to ensure that what they are dealing with is representing the individual's right and not their own personal beliefs as to what should be happening, and that there is some accountability to the public about what is going on.

**Mr J. Wilson:** It is really an unprecedented move by the government to set up an arm's-length commission that is already biased, that has a majority of its members who come from the vulnerable community. That sounds wonderful. It is almost Utopian that the commission should have this, but it does concern me, for instance, that in legislation we are actually setting up an arm's-length commission to carry out duties, and the commission itself is already biased. There is no balance there.

**Ms Wall-Armstrong:** That is what we are saying: that we are concerned that the bias of the individuals not end up going to the forefront as to how the advocacy is carried out.

**Mr J. Wilson:** Thank you.

**Mr Wessinger:** First of all I was wondering if you could refer to some of these studies with respect to the statistics on the level of cognitive impairment of persons in nursing homes. If you are prepared to provide some of these studies to the committee, I think that will be very interesting information to have.

**Ms Peppler:** The percentages I quoted are from a survey of 50 randomly selected nursing homes as well as a director of nursing consensus conference that took place last fall.

**Mr Wessinger:** And is there a report on that?

**Ms Peppler:** I have a copy I can leave with you.

**Mr Wessinger:** I think it would be appreciated, because it is certainly quite interesting information to have. It indicates the level of care that is going to be necessary in institutions such as yours.

You made some comments with respect to the question of treatment. Under the existing definition of "treatment" it is indicated that treatment includes a "course of treatment." Might I suggest to you that a "course of treatment" might cover the whole level of care that would be given to

a person in one of your facilities, and it could be given in advance by a substitute decision-maker?

**Ms Peppler:** If that is truly how it is interpreted, it would be more workable.

**Mr Wessenger:** Yes, because I think it certainly is the intention not to require continual intervention with respect to the aspect of treatment.

The other thing I might point out is, at least in my perception of the legislation, that it applies basically to health practitioners, and a great deal of the care given to residents of your nursing home is given really by persons who are not health practitioners. Is that fair to say, too? So the day-to-day living services that are provided would not be included, probably, in the concept of treatment by a health practitioner.

**Ms Peppler:** Currently people called health care aides, who are non-professional staff, work under the supervision of registered nursing staff, RNs and RNAs. They provide a lot of the personal care, and certainly it is a problem that they are not included in the definition of health practitioner because they fall outside the Health Disciplines Act. That concern is raised in our brief. There are other workers as well who are not covered under that definition of health practitioner like social workers, ambulance attendants, our activity aides who provide a lot of care to our residents.

**Mr Wessenger:** Is it your position that you would like it clarified that those daily personal care services are not determined to be treatment? Is that the position you are putting forward?

**Ms Peppler:** Yes.

**Mr Wessenger:** The other aspect I would like to bring to your attention is that you say you would like some changes in the emergency provisions of, I think, section 22 of Bill 109. Do you have any specific recommendations in that regard? I think you perhaps referred to the 12-hour aspect, but anything in addition to that?

**Ms Peppler:** I will just quote from what I said. Basically, we feel that the hours are not that useful with an elderly person.

**Mr Wessenger:** You see the 12-hour—

**Ms Peppler:** The 12 hours, yes. We would like to see something that looked at the severity of the condition and the consequences of not giving care as more of the criteria base for "emergency."

**Mr Wessenger:** Would you also support something in relation to pain, to that aspect being considered under the definition of emergency?

**Ms Peppler:** Sure.

**Mr Wessenger:** One other suggestion I would just like to make to you: You say this legislation will make things worse. It appears to me, as I understand the law now with respect to consent, that under our existing law the only provision we have that consent can be given by a substitute decision-maker is either in a hospital setting under the Public Hospitals Act, or under the Mental Health Act, or by a committee appointed under the Mental Incompetency Act. So it would appear that right now there is no provision for substitute decision-making to be made with

respect to many of the residents in your homes. Probably the only reason the system works is because of the ignorance of the existing law by people dealing with the residents. I would like to suggest that to you.

**Ms Wall-Armstrong:** There is no question that we feel there have to be changes made. Obviously right now, whether it is because of ignorance of the law from those people dealing with the residents or not, it is a procedure that people are familiar with and will continue to operate and function under. If you implement new legislation that they are made acutely aware of, you will cause a degree of confusion that will basically make the whole system dysfunctional for a period of time until they get the education, until they see how the process works. Our concern is that you could be looking at years before people get that education and before the system is reviewed to a functional basis that they can again work on it on a day-to-day care scenario.

That is what our concern is. There is no question that it needs change. As far as we are concerned there is too much that is not taken care of, but we really just do not want something hurried in that has not been looked at from a practical implementation standpoint to see how it is going to work to answer a lot of questions for people—for example, the issue about what is a course of treatment. We have medical doctors who say, "a course of treatment deals with the medication that I've offered." It does not talk about constant care for that individual, and they interpret it differently.

Unless there is something specific or unless there has been a pilot project where those things have been clearly indicated as to what they are, you are going to have a lot of anxiety by the people who are forced to work under this legislation.

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**Mr Wessenger:** I think you made the point clear that a lot of education is needed there. You would agree with that?

**Ms Wall-Armstrong:** Yes.

**Ms Carter:** I have two main points. One is the question of who needs an advocate. When you talk of people who are severely cognitively impaired, I think they would not be in question because, by definition, an advocate is listening to the wishes of the person. So the people obviously have to have wishes that they can in some way express.

You mention on page 5 that people who have no family support for various reasons should be considered clearly vulnerable and would benefit from a formal advocacy system. Also, in the previous paragraph you do concede that sometimes family assistance is of no value to the residents. Do you not agree that families can definitely be a problem in a few cases?

**Ms Bouchard:** Occasionally they can be.

**Ms Wall-Armstrong:** I would say probably the majority of the time they are helpful, but we have seen definite case scenarios where family have been of neutral benefit and some have been definitely of difficulty for the residents, just having them around.

**Ms Carter:** So in some cases the residents need another person to be supportive to them and maybe give expression

to their wishes as opposed to those of family or friends or other people who might be suggesting something different for them. So you would see that.

**Ms Wall-Armstrong:** Yes.

**Ms Carter:** Basically, I think we are looking at only quite a small number of advocates. The idea that they are going to be everywhere, interceding in every procedure, is not going to happen.

You also raised the thought that maybe there should be a pilot program. This has been suggested to us before, but as you know there already is a service in the Psychiatric Patient Advocate Office. I believe there is an advocate in each of the 10 psychiatric hospitals in the province, which seems to be working quite well. We have also had presentations from community groups which already provide advocacy on their own. They support what we are planning to do and in fact they are urging us to move ahead very quickly. We have heard the opinion expressed that this is an urgent matter, that there are people out there who desperately need this assistance and that we should not delay the legislation.

**Ms Wall-Armstrong:** I think if we had had the benefit of some pilot project in the nursing home setting, which is different from out in the community and where we feel that there is going to be a high demand, then we would probably not have a lot of our concerns because a lot of the questions we have and a lot of the confusion relating to this legislation would have been answered by that. We have not had the benefit of that in our setting, and what you are saying just reinforces the idea of at least a pilot project, at a bare minimum, in the nursing home setting or in the hospital because obviously, in other areas where they have had an opportunity to have it, they are more eager than we are to get into it, but they are dealing with it from their own setting. They have been able to answer their questions; we have not.

**The Chair:** Ms Peppler, Ms Wall-Armstrong and Ms Bouchard, on behalf of the committee I would like to thank you for taking the time out of your schedule and appearing today. Thank you.

**Ms Wall-Armstrong:** Thank you.

#### PHYSICIANS FOR LIFE

**The Chair:** I would like to call forward our next presenters, from Physicians for Life. Good morning. Just a reminder that you will have a half-hour for your presentation. The committee would appreciate it if you would limit your presentation to 15 minutes to allow time for questions and comments from each of the members. As soon as you are comfortable, please identify yourself for the record and then proceed.

**Dr Scime:** On behalf of my colleague and myself representing Physicians for Life, including those physicians who believe there is a moral basis to medicine, we would like to express our appreciation and thanks for this opportunity this morning.

My name is Dr Carmelo Scime and my colleague is Dr John Meenan. We are both family physicians. John practises in Kitchener-Waterloo, and I am from Hamilton. This

morning we are here wearing many hats: a citizen of the province, a member of the medical fraternity, a parent, and a caring family physician. Between the two of us we have been in practice for over 50 years.

We are attempting to develop for you, the members of this all-party committee, a perspective of medicine which has a moral, therefore an ethical, basis or perspective. As family physicians, we come here as patient advocates. This could very well be the most important role for us physicians. Physicians exist only for their patients, which is a distinction, not like a union and its members. A union exists supposedly for its members, attempting to increase their wages, the conditions of work and the relationships. On the other hand, physicians exist to tend to the needs of patients—sometimes curing, sometimes relieving, but always caring.

Speaking in general, these bills we are addressing this morning, Bills 7, 8, 74, 108, 109 and 110, can be seen to be directed towards that segment of the population that is approaching death or is dying. Nevertheless, death may be imminent, which is the phase of life in which death is in sight. Thus, we believe it is discriminatory. That is to say, we are focusing on a narrow aspect of life.

What we are saying is that each and every one of us in our needs or perceived needs acts as individuals and is different. But they are all treated equally. I will attempt to clarify this by reading for you the oath of Hippocrates, which is the basis of all medical oaths and all medical codes. These bills and the specific topics of death and near death that are attempting to be addressed are very popular in the medical and lay press today. We need only think of one case known to each of us, the Nancy B case in Quebec. Perhaps this particular legal presentation has catapulted this committee and the bills they are attempting to define.

As a citizen here in Ontario, I would like the members to address the issue: Do we need more laws, or do we need fewer laws? I think we can all do with fewer. Laws should not be proposed and passed as legislation unless they have clearly been presented to satisfy a particular need, not as an interference in the noble profession of medicine. Once legislation enshrines rights, they legally become difficult to change or amend. Eventually a law could be developed for its members in which an enshrined right gradually becomes obligatory.

From the preceding, what we are attempting to develop and define is this moral basis of medicine. Once we have put this across, we certainly will be able to dialogue with you, the members, who represent the concerns and aspirations of all the MPPs in the Ontario Legislature.

There is a bibliography at the end. It is for the use of your research assistants for any and all the references we make. They are easily available in a medical library or local reference library. It is our sincere hope that when it comes time for you to make your decision and vote, it will be on the basis of informed knowledge, as in informed consent.

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I would like to read to you the oath of Hippocrates, written between 480 and 370 BC:

"I swear by Apollo physician, by Aesculapius, by Health, by Panacea and by all the gods and goddesses, making them my witnesses, that I will carry out, according

to my ability and judgement, this oath and this indenture.... I will use treatment to help the sick according to my ability and judgement, but never with a view to injury and wrongdoing. Neither will I administer a poison to anybody when asked to do so, nor will I suggest such a course. Similarly I will not give to a woman a pessary to cause abortion. But I will keep pure and holy both my life and my art.... Into whatsoever houses I enter, I will enter to help the sick, and I will abstain from all intentional wrongdoing and harm, especially from abusing the bodies of man or woman, bond or free. And whatsoever I shall see or hear in my intercourse with men, if it be what should not be published abroad, I will never divulge, holding such things to be holy secrets. Now if I carry out this oath and break it not, may I gain for ever reputation among all men for my life and my art; but if I transgress it and forswear myself, may the opposite befall me."

I would like to say that those who took this oath were called physicians, but being free men in Greek times, those who did not take the oath continued their trade as barber-surgeons or killers. Margaret Mead, an anthropologist, adds a profound observation that the Hippocratic oath marked one of the turning points in the history of man. She further states:

"For the first time in our tradition there was a complete separation between killing and curing. Throughout the primitive world the doctor and the sorcerer tended to be the same person. He with the power to kill had the power to cure...He who had the power to cure would necessarily also be able to kill. With the Greeks, the distinction was made clear. One profession, the followers of Asclepius, was to be dedicated completely to life under all circumstances, regardless of rank, age or intellect...the life of a slave, the life of the emperor, the life of a foreign man, the life of a defective child. This is a priceless possession which we cannot afford to tarnish, but society always is attempting to make the physician into a killer—to kill the defective child at birth, to leave the sleeping pills beside the bed of a cancer patient." Dr Mead is convinced that "it is the duty of society to protect the physician from such requests."

My last quote is from Dr Christoph Hufeland, who lived from 1762 to 1836: "If the physician presumes to take into consideration in his work whether life has value or not, the consequences are boundless and the physician becomes the most dangerous man in the state."

I will call on my colleague Dr Meenan to continue this.

**The Vice-Chair:** Just to remind you that we would like to ask you questions. I have been looking at the brief and it seems to be pretty extensive. You have a part on the back that says "Presentation to Legislature." Would you like to refer to that or do you want to go through the whole brief?

**Dr Meenan:** If I may answer, Mr Chairman, I do not think it is the intention of my colleague to go through the whole brief. I think his presentation did take eight minutes. The points I want to make are contained in the brief and when we listened to the previous presenters, there were certain points in the legislation that we have considered. I think we see a lot of dangers and confusion in the legislation from the physician's point of view.

**The Vice-Chair:** By all means, then, go ahead.

**Dr Meenan:** Yes. As my colleague said, the problem we see is that we are dealing with the perspective of the terminal stages of life at which there is a lot of confusion and a lot of technological expertise brought to bear to prolong life. We see the power of attorney as a very powerful piece of legislation and perhaps a very necessary piece of legislation, and this is the will of the Legislature to make this a fact.

Once you study the brief, you will see that the power of attorney will inhibit the physician's ability to take care of the patient in the later stages of life. Realizing the great difficulties that physicians face in their bioethical approach to the later stages of life, I think that what we are trying to bring to bear in front of the committee and through our briefs is that we are attempting to clarify our position as physicians, as advocates for the patient.

I think this is why my colleague has accented the oath of Hippocrates, coming from a time when there was great confusion in the practice of healing, when many people deployed their healing in adverse ways at the behest of people who had unscrupulous purposes.

I think the fear is, under the power of attorney with the way the legislation is based, we could have a perspective where people who have ideas and principles which may inherently be good may be swayed by either emotion, by material purposes or may even be unscrupulous in their ways of approaching the rights of the people that they should be advocating.

One of the points I make in the brief is that a physician can interpret the patient's wishes in the terminal stages of life in a very empathetic way. Granted, the more years of expertise the physician has, the greater his or her expertise at interpreting patients' wishes and bringing them to bear in a focused manner so that they can understand completely, or as empathetically as they can, the wishes of the patient. I think this is the point we are trying to make, and I think I will terminate here and allow the committee to ask any questions it may have.

**The Vice-Chair:** Thank you very much. I did not mean to cut you short. I just saw that your brief was quite extensive and quite well-thought-out.

**Mr Poirier:** On the first page of your presentation you are talking about, and I quote out of the bottom paragraph on the very first page, "Broadly speaking, these bills"—and you list all six of them—"can be seen to be directed towards that segment of the population that is approaching death or is dying."

We have been dealing with this for two weeks, and it is definitely not only or even mainly considering those who are approaching death or dying. We are talking also about young people, those who may be very chronic long-term, with death not even close at hand. Why do you say that?

**Dr Scime:** This is our interpretation, certainly with chronic care patients in nursing homes, that kind of setting. Whether I see a patient in my office with ingrown toenails or chest pain or whatever it is, or an elderly person or I am making a house call to a nursing home or to the hospital, as I did this morning, I treat them equally. But it appears that this legislation deals with that part of life where they

may be in a degenerative phase and needing care. I treat them equally, but different.

**Mr Poirier:** Did you want to say that you wanted particularly to address that segment of the population that is approaching death and dying? The bills do not necessarily concentrate on that group of people; maybe Bills 7 and 8 do, but I think Bill 74 and others do not necessarily. So I do not understand.

**Dr Meenan:** First let me say to the honourable member that we were trying to keep an adult perspective. I understand what you are saying, and having read the bills I see the whole point. As I pointed out, the legislation has great merit. The problem is that we see this focus as being of interest to us. This is the focus we see, where the dangers are that somebody who is approaching the terminal stages of life will have an advocate, which may confuse the issue, may confuse the treatment. This is where we see the danger, and this is the perspective we are trying to bring to the committee. We can take a broad look at the bill.

But Bills 108, 109 and 110 do contain the powers of attorney, and this is something that we see reflects back to Bills 7 and 8, which contain the death and dying. But I think that Bills 108, 109 and 110 are very powerful pieces of legislation within our interpretation as medical practitioners.

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**Mr Poirier:** Your brief is obviously a very lengthy brief and very technical, and we are used to trying to read diagonally rather rapidly. I do not recall, from the short time I have had to look at it and with the size of it, if you identified very specific points and very specific subsections in any of these bills that concern you, very specific, and if you made very specific recommendations if and where you wanted changes. Did you make that anywhere in here? You seemed to have talked just about broad principles and whatever.

**Dr Meenan:** The back part of the brief is my doing, and I concentrated on the power of attorney in general terms. I did not refer to any subsections because what I derived from the bill, and not being a legal expert I derived it as a medical expert, is that I see the power of attorney in broad terms throughout the bills as being very powerful, and it needs to be addressed in more sharply focused terms.

**Mr Poirier:** Okay, but I do not recall seeing anywhere, and correct me if I am wrong, where you made some very specific recommendations as to changing of wording and whatever. Did you do that?

**Dr Scime:** No, we did not do that.

**Mr Poirier:** Okay, because I had not seen it, and maybe I had missed it. Do you plan to do that? Do you plan to submit to this committee some recommendations?

**Dr Scime:** I think the thrust behind all these bills is another layer of advocate, or whatever name you want to give to it, that will come between patient and doctor. I think that if we at all times are treating the patient according to our oath, which I am sure you know has not been taken in the last 20 years or so in the medical schools of Ontario—

**Mr Poirier:** No, I did not know that.

**Dr Scime:** Yes, there is no medical school that asks its graduates to take this oath.

**Mr Poirier:** That stopped about 20 years ago?

**Dr Scime:** Approximately. I stand to be corrected; somewhere around there. So I think that we have lost that part. If we took the oath and followed the oath in regard to what patient we see, a young child or the elderly or those who are chronically ill, those of limited abilities, we would be treating them equally and therefore we would not need somebody else to speak on behalf of the patient because we are the patient's advocate.

**Mr Poirier:** Do you recognize that there may be some situations where patients who have no family or whatever may want or may need an advocate? Do you recognize that? Do you accept that? I do not know.

**Dr Scime:** I see your point, but whether the patient in front of us has a next of kin or not, we show dignity and we show respect for that individual, regardless, as written 2,500 years ago, whether you are free or a slave.

**Mr Poirier:** In other words, if it worked for you, you would not even think of passing Bill 74 whatsoever, right?

**Dr Scime:** Yes, I would agree with that.

**Mr Poirier:** I am trying to better understand where you are coming from and where you are going. It is important for you to tell us where you stand, what you do not like, what you think is going to hinder you as a medical practitioner. But it is also important, and this is what I am trying to find out from you, for you to identify specific points in the law and, if you want to help us help you, to make some specific recommendations as to what could make it better. It is one thing to know what you do not want, but it is also important to know what you want.

So if you want to do that, you are more than welcome to do it in more detail with your colleagues, and we will consider any amendments that you want to bring forward. I can appreciate the broad feeling you have for or against certain points, but for us as legislators it is important to know exactly what particular points in the law—without you being lawyers, and we are not lawyers either—trouble you more than others and make some constructive suggestions as to changing of wording or whatever.

But if you want to leave it broad in the sense that you are uncomfortable with the principle of advocacy, that is fair enough also. We will deal with that and consider your broad sense. That is the point I wanted to make. I am trying to make it more precise as to where you are coming from and going with this whole thing, because it is quite a heavy-duty presentation, and thank you for making it.

**Mr J. Wilson:** Thank you, doctors, for taking time out of your schedules to come and appear before the committee this morning. I do not like the line of questioning; it is almost as if you are being badgered. I think you have put together an extremely scholarly, well-referenced piece which gives us a wider perspective which I think is terribly lacking around here because we are so narrow and legalistic and focused and fighting various ideologies. I certainly appreciate it.

This might be a little extreme, but you do not put a great deal of faith in advance directives. You talk about

how they properly should be used as a tool for discussion, not necessarily binding the physician. This is what I get from this. Am I on the right train of thought here?

**Dr Meenan:** I think the honourable member is partially correct, and he obviously has a good grasp of our brief. I think what we are trying to present here is the fluid situation of the medical condition as a determination of life. I think the problem is if we are somehow constrained by a legislative power which binds us to a course of decision which may inhibit the best interests of the patient and if that legislative power is not focused intensely so that there is protection that is fluid, because the situation changes moment by moment.

I know that one of the local law firms in Kitchener has asked for my input on living will legislation, which is an American concept and has been discussed within the province here. The living will can be a good thing and it can nail things down, but the problem is that advocacy or the power of attorney addressed to a patient can be so rigid and non-protective. It is hard for me to give specific situations, but we are talking for instance of a patient who has a massive coronary, who is on a respirator. What is the decision that that patient would have made previously? Would they have requested as much treatment as possible or would they have peacefully wished to go on their way to eternity? What we have to interpret for our patients is that will, that purpose, and we feel we are in the best position at this present time, and we do not see this legislation helping us.

To get back to what the other honourable member said, sure we can bring in hard-nosed points subsection by subsection, but the problem is it would have to be done so legalistically, and I agree with you that you do not want legal language. But the problem is, we are trying to give a general perspective where we ask the committee to consider the position of the physician as being truly a patient advocate at that time and within this specific perspective of the end of life.

**Mr J. Wilson:** Thank you. I appreciate that.

**Mr Winninger:** I should indicate at the outset that I think I fundamentally disagree with you on most of your points. I just want to put two brief questions to you. First of all, how many Physicians for Life are there in Ontario?

**Dr Scime:** In the hundreds, rather than thousands.

**Mr Winninger:** You do not know?

**Dr Scime:** I do not have that.

**Mr Winninger:** You do not know how many?

**Dr Scime:** No.

**Mr Winninger:** But is it less than a thousand?

**Dr Scime:** I would think so, yes.

**Mr Winninger:** Okay. Is it a formal organization?

**Dr Scime:** Yes. We are incorporated, and we have been incorporated for about 15 years.

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**Mr Winninger:** Dealing with a couple of your points that concern me, you suggest that our legislation is more directed towards death and the dying than towards life. This comes as quite a surprise to me because I had thought

that the whole role of advocacy, powers of attorney for personal care, consent to treatment and guardianship were directed towards preserving and enhancing life through appropriate interventions rather than towards death and dying. That is one thing I certainly disagree with you on. It may be a difference in our fundamental approaches. I would suggest to you that I would not be actively promoting this legislation if it were exclusively designed to promote death and dying.

However, I think you would acknowledge that there are cases where individuals, vulnerable or otherwise, for personal reasons of their own, may decide to have what we call a living will and that their individual wishes should be respected. Would you agree with that?

**Dr Scime:** Yes. For instance, in a living will you would put down that you want A, B and C. I have been practising since 1958 and I know that things have changed. Things we are doing today we were not considering in 1958.

**Mr Winninger:** You know, though, that there is a clause that allows an individual to opt for a more modern form of treatment through technological advances?

**Dr Scime:** Yes. It has to be updated because maybe there is something else along the trail, whether it is antibiotics—

**Mr Winninger:** Our legislation does not prevent that.

**Dr Scime:** No, but if we begin with the fundamental differences, if we treat that patient equally, then we would not have to put down A, B and C.

**Mr Winninger:** Okay. I know time is short and I have one other important point I want to discuss with you. Quite frankly, I have a fundamental objection to a physician who says he or she also fulfils the role of advocate. I have some difficulty with the conflict that I perceive between the person who is, with the best intentions, treating an individual and also advocating for that individual at the same time. I wonder, and I put it to you quite directly, whether you think a patient has the right to consent to or refuse the treatment.

**Dr Scime:** He or she does. But we are supposed to be professional and independent and objective and therefore we can assess the situation without becoming emotional, like being a relative or next of kin.

**Mr Winninger:** But if the next of kin or the relative or the guardian or other substitute decision-maker is making a decision that is authentic in that it expresses or reflects to the greatest extent possible the wishes of that vulnerable person, why would any physician want to interfere with that and chart a different course?

**Dr Scime:** We would not take it. I agree with everything you said. We would be arriving at the same conclusion.

**Mr Winninger:** That is not what I understood. You said you see the power of attorney as interfering with the treatment capability of the physician.

**Dr Scime:** It would be another layer. I am saying that if there was not that position we would be arriving at the same conclusion, because we would be dialoguing and talking with the family or whoever else might be represented. For those who do not have a next of kin—in the previous presentation I think they said there are about 20%

who do not have any person designated; it is usually the home or the public trustee—we would be arriving at that conclusion.

**Mr Winner:** Our legislation does not preclude anything of what you say. In fact a family member would be a preferred guardian in the majority of cases. That dialogue could continue and that family member would have formal guardianship to make the kinds of decisions you would probably deem necessary.

**Dr Meenan:** With the Chair's indulgence, one point: The phrase you use is "interfere with treatment." I would rather say "inhibit treatment" and I think I implied that. Okay?

The other point is that with a power of attorney, at the moment bilateral discussion goes on all the time and we take into consideration very seriously what the family says. It is binding on us on an ethical basis. But the problem with a power of attorney is that it is a constraint on that person. Unless it is interpreted very, very minutely and adequately it inhibits treatment all along and can prolong treatment unnecessarily at tremendous emotional cost to the patient, and to the family if the patient is comatose. Rather than "interfere," I would rather use the word "inhibit."

**Ms Carter:** My points are very similar to what Mr Winner has raised: first of all, that not all vulnerable patients are close to dying; and second, although I am sure doctors do try and in most cases succeed in being professional, independent and objective, nevertheless there sometimes are decisions to be made. There are different directions to go in. The decision is sometimes very properly to be made primarily by the patient or those speaking for the patient—for example, where you have to choose between taking medication which might have drastic side-effects and not taking it. We have listened to a lot of representations from schizophrenics and relatives of schizophrenics and we have had two very different views on that question. Individuals have a right to be heard on that.

Then there are cases, for example persons who might be Jehovah's Witnesses and not want blood transfusions, where their own best interests from your point of view and what they actually want are in direct conflict. Do you have the right to override that decision on their part? I think it is much less of a clear-cut case. You see it from your point of view. I am sure you always try to do the best, but I think in the real world we cannot say for a doctor to be their own advocate is good enough and just leave it at that. Sometimes it does need decisions to be made with input from other directions.

**Mr Malkowski:** I thank both presenters today for providing that comprehensive perspective. One medical professional from the west was talking to me about the situation where the doctors in the west were on strike, and statistics had shown there was actually a decrease in the rate of death. Another situation is that some medical professionals at times certainly do have the power to decide life-and-death situations and where things are going to stand in those situations. Do you agree that it is important to provide the patient with information on some of the possible risks involved in treatment? There are times

where the treatment actually can have detrimental effects. Do you not feel that patients need to have all that information provided to them?

**Dr Meenan:** If I may answer that, with respect to the honourable member, I think he is talking about the Israeli doctors' strike in 1959. I do not know about the strike out west, but there was a definite reduction in the number of deaths during that strike, which was no surprise because probably nobody had been operated on; nobody had been treated. There probably were no iatrogenic deaths. The point you make is very good.

As I said, there must always be bilateral discussion. Patients must know exactly what the treatment is and what is happening. Only the patients can be totally empathetic to their own cause and only—with due deference to the committee—a professional can in some way empathize far more than, unfortunately, the family members. Family members give input and try to see the patient's wishes, but so often over our experience we have seen family members being confused, being hot and being put in corners by other family members. They need some kind of overall position that advises them as to the best course of treatment for the relatives who are incapable of understanding, who are comatose or who are at the end of life. They need this interpretation.

**Mr Malkowski:** But in some situations there are patients who do not have family and relatives. They may need a neutral person to also explain information to them. Do you not agree that that situation can happen?

**Dr Scime:** That is quite correct. What we are trying to impress on you is that if we followed our oath—we are professionals; we are independent; we only exist for the patient—certainly we would be giving the patient all the information that is possible, the pros and cons we arrive at, so that the patient and the physician arrive at the proper course of action. I hope that helps you.

**The Chair:** Dr Meenan and Dr Scime, on behalf of this committee I would like to thank you for taking the time out of your busy schedules and coming to give us this presentation.

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#### UNIVERSITY OF OTTAWA

**The Chair:** I would like to call forward our next presenter, Professor Cynthia Petersen. Good morning. You will be given a half-hour for your presentation. The committee would appreciate if you would limit your remarks to about 15 minutes to allow time for questions and comments. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Ms Petersen:** My name is Cynthia Petersen. I am a professor of law in the common law faculty at the University of Ottawa. I specialize in the area of lesbian and gay rights. I teach a course on lesbian and gay legal issues. I have published in the area and I also do a lot of consultation in cases involving lesbian and gay litigants. I am also a lesbian, so I personally have an interest in seeing that the law treats lesbians and gay men equally.

My remarks will be fairly brief. They are specifically to address the definitions of the words "spouse" and "partners" in Bills 108 and 109, the Substitute Decisions Act and the Consent to Treatment Act. Both these bills have an identical definition of the word "spouse" and of the word "partners" in them, so I will just treat the two together.

Both bills indicate that in some circumstances the spouse or partner of an incapable person may be authorized to make decisions on his or her behalf. The concern I have is with the content of the definitions. I have indicated on page 2 of my brief the current proposed definitions. You will see that the word "spouse" is limited exclusively to individuals of the opposite sex. They may be married to each other, they may live together for one year, have parented a child together or have entered into a cohabitation agreement under section 53 of the Family Law Act.

Partners, on the other hand, do not necessarily have to be individuals of the opposite sex. The definition that is currently given in the bills is, "Two persons are partners for the purpose of this act if they have lived together for at least one year and have a close personal relationship that others recognize is of primary importance in both persons' lives."

The way that I read the legislation, the definition of "partners" is an attempt to expand the scope beyond the traditional heterosexual nuclear family model so that individuals who do not structure their families in that way may nevertheless be recognized as partners, and individuals may have an opportunity to be authorized to consent to treatment or to consent to make certain decisions on behalf of their partner who may be incapable according to the law.

My first concern is that the definition of "spouse," as you can see, is much broader than the definition of "partners," in the sense that individuals of the opposite sex can be recognized as spouses under four different categories, whereas individuals who are of the same sex would only be recognized if they met the definition of "partners," which is much more narrow. For example, two heterosexual people, a man and a woman who had not lived together for a year but who co-parented a child or who had a cohabitation agreement together, would be recognized as spouses, whereas a lesbian or gay couple in the same circumstances could not be recognized as spouses because there is a mandatory one-year cohabitation requirement.

Furthermore, all the other categories are excluded. Marriage is obviously excluded because it is not possible under the law, but a lesbian couple could enter into a cohabitation agreement. It would not be recognized by section 53 of the Family Law Act, but the fact that the act discriminates against lesbian and gay couples I do not think is any reason to justify the perpetuation of that discrimination. Certainly lesbian or gay couples can co-parent children just as easily as heterosexual couples can, so there does not seem to be any reason why we should differentiate in that regard.

The other concern I have is specifically about the cohabitation requirement. Even if it were imposed on heterosexual couples so that it were mandatory—which it currently is not, the way the bills have been drafted—a heterosexual couple does not need to live together for a year if for example they have a cohabitation agreement. But in my opinion, even if it were imposed as a mandatory

requirement it would still discriminate against lesbians and gay men, because they are differently situated in our society. Oftentimes cohabitation is simply not a viable option for a lesbian couple or for a gay male couple.

First of all—I think this is well known—there is widespread discrimination, oftentimes harassment, and sometimes outward violence against lesbians and gay men, who as a result sometimes choose to conceal their sexual orientation from certain segments of this society. Living together as a couple oftentimes creates a greater risk that your sexual identity or sexual orientation will be discovered by the public. So if as a lesbian person a woman chooses not to live with her lover so that, for example, her family will not guess that she is involved in a lesbian relationship or so that her friends or colleagues at work, other tenants in the building, whatever—if she chooses to conceal that from them, one of the things she may do to conceal her sexual orientation is choose not to live with her lover.

In Ontario we do have some human rights protections against, for example, being evicted from your apartment because you are lesbian or because you are gay, but the Human Rights Code does not protect against harassment based on sexual orientation, so we do not have full protections in the province. It may be very legitimate for lesbian women or gay men to choose not to live with their lovers in order to increase their ability to conceal their relationship, and hence their sexual orientation, from various people in their lives.

The other concern I have, which perhaps is more critical, is that currently the judiciary in Canada often imposes a non-cohabitation requirement upon lesbian mothers or gay male fathers who have custody of their children. When a heterosexual relationship breaks up and the parents are involved in a custody dispute, usually the lesbian mother or gay male father is at a disadvantage. I am speaking now of someone who was involved in a heterosexual relationship and comes out as a lesbian woman or as a gay man.

The judges in Canada have said consistently that homosexuality or lesbianism is not a bar to custody, and for the most part they have not prevented individuals who are gay or lesbian from having custody of the children merely because they are lesbian or gay. But it is very common and regularly imposed that they cannot live with a same-sex lover if they are going to maintain custody of their children. So this legislation would essentially force lesbian mothers or gay male fathers who have such a conditional custody order with respect to their children to choose between maintaining custody of their children and being recognized as partners with their lovers. This, I think, is probably not something that was deliberately inserted into the law. It was perhaps just an oversight, but I do want to bring that to your attention.

The last thing I wanted to bring to your attention is the fact that the current federal law does not permit lesbians and gay men to sponsor their partners into this country for the purposes of immigration, and so an individual Canadian lesbian or gay man whose partner is in a foreign country faces considerable obstacles in getting that person to come and stay permanently in Canada. So, again, to impose a cohabitation requirement upon them does not seem to be fair.

All of these obstacles are something that heterosexual people do not face, so it simply does not mean that you are treating people equally if you impose the same condition on both, because lesbians and gay men are situated differently.

The final remark I wanted to make is with respect to the requirement under the definition of "partners" that the relationship between these two individuals be one "that others recognize is of primary importance" in both of their lives. I do not understand the imposition here that there needs to be some form of societal validation or even just societal recognition of the relationship. A lesbian or gay male couple may choose to conceal their relationship for a variety of reasons until they are actually confronted with a situation where one of them has become incapable. At that point they may be willing to come forward and come out with the relationship, but they should not be required prior to that point to necessarily disclose their relationship. That is what this legislation does. It also implies that there has to be some form of acceptance from others that they are of primary importance to each other's lives, and it simply is not fair in our society, where lesbian and gay relationships are not respected for the most part. There is a lot of hostility and lack of recognition, lack of respect.

The alternative appears on page 7 and 8 of my brief. First of all, I suggest that you eliminate the distinction between spouses and partners. I think it marginalizes partners, and I do not understand the necessity of it. Furthermore, I think it risks creating a conflict when you have an incapable person who has a partner under the definition presented here and at the same time may remain legally married to someone else from whom they have been separated for some period of time. Then you will be forced to make a decision about who gets priority between the spouse and partner.

I think it would be easier if you simply eliminate the distinction, completely repeal the definition that is presently put forward for the word "spouse" and substitute for the current definition of "partners" the one I have on page 8 of my brief, which I will read to you: "Any two persons are partners for the purpose of this act if they have a close personal relationship which is of primary importance in their lives. Factors which may be considered as indicia of partnership are: shared accommodation, sexual relations, a coparenting arrangement, a cohabitation agreement, shared activities, shared finances, self-identification as partners or a marriage contract. This list is not exhaustive and any absence of any of the enumerated indicia shall not preclude recognition of partnership."

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I began the definition with the word "any" to indicate that it would include both opposite-sex and same-sex individuals. I do not require that the cohabitation agreement be recognized by section 53 of the Family Law Act, because that would further discriminate against lesbians and gay men. I do not demand that any of the particular indicia be necessary for partnership to be recognized; just that it be taken into consideration when a decision is to be made as to who constitutes a partner or a spouse of an incapable person—in these circumstances a partner. That is the essence of all of my remarks.

**Mr Poirier:** I could not agree more with you. I do not understand why there is a distinction, English being my second language. Why the hell does the law make it that a spouse becomes automatically heterosexual?

**Mme Petersen :** Vous pouvez m'adresser en français, si vous voulez.

**M. Poirier :** Pas de problème, mais on n'a pas de système d'interprétariat ; donc nous on va se comprendre, mais il y a peut-être d'autres personnes qui ne nous comprendront pas.

So until we get our pacemakers here on a regular basis so we can talk English or French as our choice, we will just do it in English for right now.

I do not understand why the law says that a spouse is then enshrined as something heterosexual, and partner, homosexual. I do not understand that. With all due respect to what the law said in the past, that in 1992 you make this distinction I do not understand.

Second, I do not understand people from a party that has always been on the rooftops telling us that they respect people who are heterosexual, homosexual or whatever, that lesbians and gays and whatever have big support among this party, that they would come forward with this type of bill to make this distinction. To me a spouse can be same sex, opposite sex; I respect that. Same with a partner. I have had a partner before, and I am not homosexual. That is the way I see the definition of the word "partner" or "spouse." You are saying with this definition on page 8 that people are partners—or spouses, I guess—whether this could be considered for same-sex or opposite-sex relationships, right?

**Ms Petersen:** Yes.

**Mr Poirier:** Okay. So why would you not say "partners or spouses"? Who gives a damn what the definition is?

**Ms Petersen:** Right. Well, I would be open to that. The main thrust of my presentation is that I do not think there should be a firm distinction between spouses and partners, and certainly that the criterion should not be different for spouses and partners, but if you want to call it spouses instead of partners, I am not opposed to it.

**Mr Poirier:** Or something that would say that you can call it a spouse or you can call it a partner.

**Ms Petersen:** If anything, I was anticipating that some individuals may take offence to calling lesbian and gay couples "spouses" as some heterosexual individuals do, and so I was suggesting partners—

**Mr Poirier:** Too bad.

**Ms Petersen:** —as an alternative.

**Mr Poirier:** That is their problem, not yours and mine, right?

The other thing is: For others to recognize it as a relationship, who the heck is going to define "others"? Are you going to have a list as to who qualifies to be the other to recognize that relationship? It does not make sense either. So if you are the party of the people that claims to have a more sensitive nature as to the respect of—which is not true; which I do not believe—then you should come forward and rewrite this and eliminate this kind of crap. Pardon the expression.

**Mr Chiarelli:** Thank you for bringing these things to our attention. Quite frankly, the distinction did not come to mind when I read the legislation. The substance of the act as written, I think, shows the intention, as you have agreed, but I think that as legislators we have to be prepared to look at new ways of defining and taking into account social and practical realities that are out there.

My question to you is, is the present definition section assailable or can it be attacked, as you understand any human rights codes or laws applicable to the province of Ontario?

**Ms Petersen:** It depends on the interpretation you give. Currently the Ontario Human Rights Code does prohibit certain forms of discrimination based on sexual orientation, but the definition of the word "spouse" within the Ontario human rights act remains exclusively heterosexual. It has been judicially interpreted as not being available as a recourse for lesbian and gay couples. The human rights act is not available as a recourse. If you are a lesbian who is, for example, fired from your employment because you are lesbian, yes, there is recourse, but if it is a matter of a spousal benefit that you are seeking, generally the law has not been available.

I do not think that is a reason, however, not to change the law. If anything, it means we also need to change the Ontario Human Rights Code so that it provides greater protection for lesbians and gay men. But I would say in my professional legal opinion, no, I do not think you could actually attack it based on the Ontario Human Rights Code.

**Mr Chiarelli:** I think, looking at the rationality of your argument and looking at the legal technicalities of your argument, you are 100% correct, but I am sure you understand that there is also a political reality. The challenge is, is the government prepared to accept the rational, legal recommendations that you are giving in light of some of the political realities and special interest groups and so on and so forth? It is going to be interesting to see how we respond to your suggestion. I want to compliment you on your presentation, because technically, legally and rationally it makes more sense than what is in the bill at the present time.

**Ms Petersen:** I think you also have to remember that part of the political reality is that there is also a large lesbian and gay lobby in the province.

**Mr Winninger:** I think I can accept most of what you say. I know I can also say that the government is actively reviewing the wording of this definition, to come up with a better definition.

I do have a couple of questions arising out of your submissions, though. One is just to satisfy my own curiosity. If you are weighing these various indices—and I take it it would be a judge who would weigh these indices—

**Ms Petersen:** Presumably if there was some sort of dispute it might end up before a judge, but hopefully you would not reach the stage where there would be a dispute. Somebody would clearly be recognized as a person's partner or spouse, whatever term you want.

**Mr Winninger:** You may have been reading my mind, because I could see how several different people

could come forward with various permutations or combinations of these indices you have described and all ask to be made the guardian or to be enabled to consent to treatment. Is that a scenario?

**Ms Petersen:** I think that is possible. I do not think that is something that would occur regularly, but it is certainly something that in a given situation could be possible. But it is also something that currently exists under the law and already happens, so it would not be creating some sort of difficulty that does not already exist.

**Mr Winninger:** Except that you are making the clause a little more general than presently exists.

**Ms Petersen:** With respect to heterosexual individuals, yes, but with respect to lesbian and gay individuals, I do not think it really makes it all that more general, because the current definition of "partners" is already in some respects quite vague except for the one-year cohabitation requirement.

**Mr Winninger:** I see.

**Ms Petersen:** But certainly with respect to heterosexual individuals, I think yes, it does make it a little bit more general in the sense that there were four clear categories before and if you met one of them you would automatically be considered. But then again you could also be married to one individual and coparent another and have two spouses under the current definition.

**Mr Winninger:** Right.

**Ms Petersen:** I do not think it creates more difficulties than already exist, although I will not deny that the possibility is there that two people may present themselves.

**Mr Winninger:** There was something else I wanted to put to you. In terms of the present wording of subsection 1(2) of the proposed definition, you would agree with me that the reference to partners does not connote or refer to sexuality.

**Ms Petersen:** Not particularly.

**Mr Winninger:** It is sexual orientation-neutral.

**Ms Petersen:** Yes, I agree; it could include two heterosexual individuals. It does not specify necessarily that it is a lesbian or gay couple that would constitute partners.

**Mr Winninger:** Okay. Last, I do not think you need to be reminded that it was our party when in opposition that advocated the amendments to change the Human Rights Code to prevent discrimination in services and accommodation for lesbians and same-sex partners.

**Ms Petersen:** In fact I am in favour of the spirit of the law. I see this as a movement towards recognition of lesbian and gay couples as well as other individuals who do not live in traditional family structures. I just think it is flawed. But I do see it as a movement in the right direction, because the law could have been written without the definition of partners, in which case it would have been exclusively heterosexual. I think this is a step in the right direction, but I do think that it is flawed.

**Mr Winninger:** Thank you.

**Mr Chiarelli:** The present definition, when you are looking at heterosexual relationships, could also be

discriminatory, could it not? In other words, there are presumably multiple relationships or conflicting relationships, triangles or what have you, whereby the definition of spouse could in fact create an injustice on the relationship. Who is the person of primary importance to an individual? A person of primary importance in effect is not necessarily the one who fits the definition in subsection 1(1).

**Ms Petersen:** Yes.

**Mr Chiarelli:** Mind you, there will be a minority of circumstances, but can you see circumstances where in fact a spouse ought not to be the person of primary importance?

**Ms Petersen:** Certainly. If it is a person to whom you are legally married but from whom you have been separated for a number of years or there is some sort of distance between the individuals, the mere fact that there remains a marriage bond that has not been dissolved I do not think should be privileged to the extent that it would be with this current definition, which is why in my proposed definition a marriage contract is only indicia of partnership.

**Mr Chiarelli:** It could be more unfair to the heterosexual situation as well. You may have people who are cohabiting together, legally married for whatever reasons, and there is a more meaningful relationship with somebody outside that house in a heterosexual context.

**Ms Petersen:** Yes, I suppose it is possible, because people live in all different circumstances, so certainly it is possible.

**Mr Chiarelli:** I know of some, particularly, where that would be applicable. So therefore the definition as it presently exists in subsection 1(1) could create an inequality or an injustice.

**Ms Petersen:** Yes. I would agree with that.

**The Chair:** While I do not usually get involved in these things—and I will not make a comment—I have one question. Somebody who is hiding his or her sexual orientation—if something happens and the family shows up and they know of no other significant other, what would happen in that case?

**Ms Petersen:** Then the person would be forced to disclose the relationship, and it is usually what happens in these types of contexts where—

**The Chair:** But what rights would they have? Where would there be any clear indication that they are the person, the significant other?

**Ms Petersen:** Are you talking about under my proposed definition? The law as I would like to see it?

**The Chair:** No. Just what your solution would be in that case. Would a living will be your only alternative?

**Ms Petersen:** No. I do not think it would necessarily be the only alternative, although those sorts of documents can sometimes be very helpful. If the family was not aware of the relationship because it has been concealed from the family and now suddenly this person presents himself or herself—they may have been presenting themselves as partners to other circles of friends. For example, the family may not have known about the relationship. There are other people who can come forward and say, “We know they’ve been having this relationship for a number of years.” They may have been sharing their finances and not telling their parents, siblings or whomever about it.

Yes, the family has been left in the dark, but nevertheless they have met a number of the other indicia who could then come forward and indicate partnership. So I think that most lesbians and gay men who conceal their relationships do not conceal it to the point where there is no one in their lives who knows about the relationship, although they may choose to keep it from their families or one of their two families. They usually tend to conduct their lives very much like any other couple and share activities together or perhaps share accommodations or maybe not. I think that in all likelihood they would still meet most of the indicia. If they did not, then you would have to resort to that sort of document.

**The Chair:** Thank you for that clarification.

Professor Petersen, on behalf of the committee I would like to thank you for taking the time out today and giving us your presentation.

**Ms Petersen:** Thank you.

**The Chair:** This committee stands recessed until 1:30 this afternoon.

The committee recessed at 1205.

## AFTERNOON SITTING

The committee resumed at 1343.

JUDITH SNOW

**The Chair:** I call our first presenter, Judith Snow. Good afternoon. Please identify yourself for the record and then proceed.

**Ms Snow:** My name is Judith Snow. I am with the Centre for Integrated Education and Community, but that is not who I am really representing today. I am representing a group of about 150 families, each of which has a child or a member of the family who does not speak. We do not have a formal name as yet in Ontario, although the group has existed for about 15 years and operates on a very informal basis.

This group invented the idea of building support circles around people as a means of supporting their participation in society without necessarily having to be dependent on services and formal associations.

The group came into being because the families that have these children were finding that the formalized services were isolating and segregating their members rather than facilitating participation of those people. I am talking about people who would be labelled in the system as severely and profoundly disabled, people the new advocacy legislation would say were incompetent and would require being labelled as incompetent in order to receive advocacy services.

By the way, two things that are quite noteworthy in Ontario grew out of this group. One is the Citizen Advocacy movement in Ontario and the other is the Extend-A-Family movement. Extend-A-Family is a formal organization that finds friends and families to be partners with the families that have a person who does not speak as a member. As a model it was developed in Toronto, but it has become a worldwide model for supporting people who are considered to be severely disabled or developmentally disabled in some way.

This group met about six months ago now—how time flies—addressed the issue of the advocacy legislation and was quite concerned about the impact this legislation might have. A small group of us decided that one of us would make a presentation, and here I am. I also wrote a paper, which I presume you have in your package somewhere. It is called Empowerment Through Advocacy.

Very simply—I hope very simply—what I would like to say is that we really are in the grips of two paradigms, two ways of thinking about what a person with a disability is in society and what is the best way to approach providing the kind of support and protection we all want to provide. Our concern is that all the legislation that lies before you comes from the wrong paradigm and consequently, even though we might tinker with it endlessly, we are not likely to get something that would really work for a person who does not speak. I would like to lay out those two paradigms very briefly.

To be perfectly honest with you, if I had my way we would just drop all this stuff and start again from a different point of view and really look at what it is that could really serve somebody who requires protection. I doubt

very much that this is going to happen, but I think it is important for us to realize that further labelling somebody is not likely to end up with actually supporting him in any particular way. Let me explain how that is.

The one paradigm I call the “disabled” paradigm. It is the idea that whenever we see somebody who clearly has a limitation, who cannot walk, talk, figure out how to put his pants on right the first time, who has some kind of limitation, when any citizen sees or encounters that person, the first reaction is a very compassionate one, generally speaking. They recognize that the person is going to be unable to make use of society, as society is, and is going to experience real limitation. As a society, as citizens we say: “We’d like to do anything we can to help you overcome that limitation so that you’ll have the same opportunities and options as other people. When you’ve overcome your limitation, we’ll welcome you into the bosom of society as a ‘normal’ citizen.”

Out of that has grown an incredibly wide range of opportunities for people. What we have in fact is a community within a community, so that if you are a person who is labelled disabled, you can literally access another form of transportation, another place to live, another place to spend your day or to work, another set of recreations, a completely different set of opportunities from what the ordinary citizen encounters, built one within the other, a community within a community. I am talking in very black and white terms, but I am just laying out the basic idea. What is supposed to be possible is that when you have gotten what you can get out of the special system, then you will have access to the ordinary system.

1350

That would be great, except for one thing: It does not work. Nothing in the special system ever actually helps somebody overcome his limitations. That is not to say that it does not change that person, quite dramatically sometimes, but a person who does not speak—I mean 99% of the time or more—is still a person who does not speak after 15 years of special education, or a person who does not walk is a person who does not walk after eight or 10 years of rehabilitation. After five years in the chronic care system an elderly person is still an elderly person; in fact, they are five years more elderly.

The system does not work. We have put so much time and energy into it that we as a society find it very difficult to recognize that it does not work. But its aims and its objectives are still quite valid; that is, that what we want to do is help people overcome limitation so that they can be participators in the ordinary world.

The other paradigm we call the “gifted” paradigm. It says that everybody is already participating and making a contribution to society. The issue is not overcoming a limitation of the person, but overcoming a limitation in the supports and the relationships around the person so that, first, people see that the person is contributing and, second, his contribution is enhanced and offered more fully to society than it is right now.

For example, in our larger institutions, of which we still have a few in Ontario, everybody who is in the institution spends some part of his day doing something like being part of the messenger service, the cleaning staff, the foodservice system, the laundry system, doing some of the landscaping or something like that. For example, at Huronia Regional School—whatever they call it these days—all of the residents participate in one of those five activities each and every day. While they are there they get paid \$60 a month, they get told that they are severely and profoundly disabled and that we think they are a burden to society. If they happen to be living in their home community, surrounded by family and friends, they could be doing exactly the same job, literally exactly the same job, being paid \$12 to \$15 an hour or more for it, and people would see that they are actually making a contribution to society. The possibility would be there for that contribution to be enhanced. For example, they might go from part-time to full-time work. In any case, something could happen that would enhance their participation.

As another example, we say that children who do not speak and apparently do not do anything are severely and profoundly disabled. Yet in three or four school boards in the States that have actually integrated such children into their regular classrooms the rate of violence in the high schools has dropped dramatically. We do not yet know what the direct connection is between putting a child who does not speak into a classroom and the dropping of the rate of drug use, but clearly there is a relationship, and we need to find out what that relationship is. But it looks like the high school kids take such an interest in the activities and participate in supporting this child in the classroom that they no longer feel their lives are worthless and that the best thing to do is either to take drugs or kill somebody in the school yard.

Those of us who are interested in supporting people who do not speak say that labelling somebody as incompetent in order to protect him is just going further down the road towards pushing this person into a very segregated situation and causing him to be seen as a non-participant in society. We value the fact that people want to make an effort to protect people in our society, but we feel it would be much more productive to put something in place that would allow us to support relationships around people. Something like the Citizen Advocacy and the Extend-A-Family models need to be enhanced in our society and made more available to people than they are now.

The fact is that if somebody is part of a powerful relationship network of people who respect him and know what his contribution is, then good decisions will be made for and about him in that circle of people. What is missing for a lot of people is that their relationships have been stripped out of their lives, for one reason or another. Very often it is because of the actual services they have encountered.

For example, if you get to become a quadriplegic in our society, you are put in the hospital for at least two years. During that period of time your family, your friends and the people you go to school with and the people you work with tend to drift away from you because you are not participating actively in the same activities that you were

before you became a quadriplegic. But other rehabilitation models get people back up in wheelchairs, give them an environmental control, and send them back to school within two or three days, still stabilizing them medically but doing it in an outside model rather than an in-hospital model. When something like that goes on, people keep their friends and keep their relationships, keep their important activities and maintain their role in life.

We are saying that where the energy needs to be put is around maintaining and enhancing the relationship networks that are around people who do not speak, rather than having them labelled incompetent.

**Mr J. Wilson:** I am sorry I was not here for the first part of your comments, although I am very interested in what I have heard. How does the role of an advocate fit into your thoughts, then?

**Ms Snow:** The primary role of advocacy around somebody who is stripped of relationships would be two things. One would be to prevent somebody from being moved out of their relationship network, if at all possible, and then if somebody was already isolated, say in a nursing home or an institution or whatever, then the role of the advocate would be to start rebuilding relationships around people, much as Citizen Advocacy does now.

**Ms Carter:** I have a great deal of sympathy for your point of view. I am just wondering how as a government we could legislate to help bring about the kind of situation that you are describing. What could we do?

**Ms Snow:** I do not think there is a quick answer. I think we need to seriously rethink the model that the advocacy legislation is built upon. Second, funding supports like Extend-A-Family and Citizen Advocacy need to be considered as a genuine part of what is happening, because traditionally funding for the relationship supports is the hardest sort of funding to get.

**Mr Malkowski:** As always, your presentation was very interesting. Just in relation to advocacy, you had said that in fact it is something that is necessary for the community to develop strategies for, for example regarding the application of provision of advocacy. Can you expand a little bit more about how you see the community developing that, and what benefits do you see, then, in these provisions for vulnerable individuals?

**Ms Snow:** The strategies I am most familiar with are building support circles around people who have become isolated, recruiting volunteer citizen advocates to represent people's needs and interests, and also recruiting facilitators to build support around people when they are missing. I do not think by any means that those are the only strategies that might become possible if a large number of people actually sat down and said: "Okay, how will we prevent people from becoming isolated in our society? What will we do to rebuild their networks when they have become isolated?"

I guess the only other thing I would like to say about vulnerable people is that what makes them vulnerable is not their disability but their isolation, the fact that people do not see them as having any valuable contribution to be making even when in fact they may be making that contribution right under people's noses, but people do not recognize it.

Something needs to be put in place that allows people to see that people are already contributing, and that their contribution is valuable, and that that contribution could be made more powerfully if they were placed in the community and properly supported. Then they would not be so much at risk.

**Mr Malkowski:** Just another question in relation to how you feel about some of the physicians who are doing medical research, for example on disabled individuals who have been labelled incompetent—just your personal view on what we have heard on those issues.

**Ms Snow:** I was involved in a court case almost 10 years ago—about eight or nine anyway—where a doctor at Queen's University was doing medical research on people on Onondaga without written permission and actually training students by using the bodies of these people without their permission. The law, as it exists now, revoked her licence. I think that was the right thing to do. I do not know whether we need new laws to be able to do that. What we need is for people to be more aware of the fact that when people are isolated in services and in institutions, they are incredibly vulnerable to that sort of abuse.

**The Chair:** On behalf of this committee, I would like to thank you for taking the time out and giving us this presentation today.

1400

MOSHE GREENGARTEN  
DONALD STUSS  
DAVID CONN

**The Chair:** I would like to call forward our next presenter, the Baycrest Centre for Geriatric Care. Just a reminder that you will be given half an hour for your presentation. The committee would recommend that you limit your remarks to about 15 minutes to allow time for questions and comments from each of the parties. When you are comfortable, could you please identify yourself for the record and then proceed.

**Dr Greengarten:** My name is Moshe Greengarten. I am with Baycrest Centre for Geriatric Care. My colleagues are Donald Stuss and David Conn.

I mentioned to the clerk that what has been circulated to you is not the formal submission of Baycrest Centre for Geriatric Care. That is a submission of the Baycrest competency clinic, which is a component of Baycrest Centre. I just would alert you to that.

My colleagues and I are pleased to have the opportunity to make this presentation to you. I will be commenting on certain aspects of Bill 74. Dr Stuss's remarks will focus on problems posed for Alzheimer's research and Dr Conn will have something to say about non-emergency medical treatment of incapable patients and the assessment of incapacity.

As we noted in our written submission to you, vulnerable persons and persons who are incapable of making certain decisions constitute a large and varied group of people, including the frail elderly, developmentally handicapped, physically disabled and psychiatric patients.

Our expertise lies primarily in the area of the elderly and we have limited our submission to this population. It may

well be that the issues we raise have little or no bearing on other vulnerable groups. However, we believe that failure to address these concerns will have significant negative consequences for older adults and their families in Ontario.

We have many specific concerns about the Advocacy Act, which we have outlined in our brief, including its failure to identify the specific advocacy model to be implemented, the need to establish the qualifications of advocates, the apparently costly and bureaucratic nature of the advocacy system, the excessive powers of advocates, and the potential for duplication of service between the advocacy program and the new service coordination agencies planned as part of the redirection of long-term care services.

However, our single greatest concern rests in another area. While there is clearly no intent to do so, Bill 74 defines an advocacy system which is highly adversarial. We are concerned that the proposed universal approach to advocacy will set up confrontational relationships within families, setting family members against each other and against their vulnerable relatives. Except in extreme situations, an advocacy program should be supportive of family relationships and of care-giving relationships generally, including those involving providers of health care and social services.

The adversarial nature of the proposed program seems to be implied in the powers granted to the advocate, including the right of entry and inspection of records. The only justification for such excessive powers would be evidence of wrongdoing or abuse. Yet the proposed legislation does not require that such evidence be demonstrated in a court of law. The only other possible inference is that such powers would be used for fishing expeditions. Unbridled powers of entry and access to records can only lead to an adversarial relationship between advocates and facility-based care givers.

In sum, successful advocacy programs should be based on relationships of mutual respect and confidence, with a view to protecting the rights of individuals while preserving intact to the extent possible formal and informal care giving and nurturing relationships. It is this type of approach which will in the long run lead to an improvement in the condition of vulnerable persons in this province, both on an individual and a systemic basis.

It is therefore our view that the introduction of advocacy legislation should be delayed until there is further investigation into the most appropriate advocacy program for older adults in Ontario. We caution that amendment of the Advocacy Act is not sufficient; a rethinking of the entire approach is necessary.

At the same time, Bills 108 and 109 should be amended to remove reference to the advocacy system. With the exception of the area of non-emergency medical treatment, which will be addressed by Dr Conn, all of the identified areas of involvement of an advocate in Bills 108 and 109 also involve either the public guardian and trustee, the courts or the Consent and Capacity Review Board. It would therefore appear to be more efficient and effective for these bodies to intervene if there are reasonable grounds to indicate the need for intervention rather than to assign responsibilities to the proposed advocacy program.

**Dr Stuss:** My name is Don Stuss. I am vice-president of research at Baycrest Centre for Geriatric Care and director of research at the Rotman Research Institute of Baycrest Centre.

I would like to say at the beginning that I believe that there are very positive aspects to the bills in question. Some of the questions I am going to raise may be on my own personal misinterpretation of the bills. However, it is also my understanding that the purpose of this committee is to hear concerns about problematic issues and/or ideas and ways to improve the bill. I wanted to present to you three assumptions and some of the problematic issues that these bills in question present as they relate to research, particularly with regard to the incompetent elderly individual.

My first assumption is that appropriate treatment and adequate care of patients are based on knowledge, and the validity of this knowledge is proven through research. Throughout history, advances in all aspects of health care have resulted from the validity and research into the efficacy of many aspects, such as treatment, management, and health care attitudes.

Second, if this is true, one should also realize that knowledge is incremental and often developed in small building blocks. The bills as written, as I interpret them, would stop all research in the incompetent and frail elderly individuals for this century and likely beyond. It is unlikely that individuals will respond to the request to sign advanced directives, even after a large-scale public education program. I think this has some serious consequences.

As a researcher, I can tell you seriously that we would rapidly lose our core of established researchers and the best clinicians who want to do research will leave the province to work in other domains. We would not develop young researchers. We would not have constructed the essential building blocks to maintain the adequate base of knowledge required to maintain care. The necessary consequence will be eventually deteriorating levels of care for the vulnerable, incompetent, elderly citizen of this province.

Third, necessary research involving the frail and incompetent elderly includes both non-invasive and invasive procedures. Much research into dementia, for example, involves non-invasive tests, such as memory and cognitive functioning, to understand how people's abilities alter with these disorders, but other research into the elderly with dementia may involve some invasive aspects. For example, if one wants to validate a treatment for Alzheimer's disease, it would require the taking of blood, which would be considered an invasive procedure since it would not be done for a clinical reason. It appears to me, however, that such research is essential to the understanding of failing cognitive abilities and essential if we are ever going to come up with a treatment that will hopefully lead to both improved care and such treatment.

1410

I think it is important to understand that we cannot assume that the principles of care and treatment for younger adults will necessarily apply to the elderly. As the population of this province ages, and particularly as the number of elderly adults of 80 years of age and over is expected to increase dramatically over the next several decades, problems such as Alzheimer's disease, other types of dementias

and the medical and health problems associated with aging will reach, I think, epidemic proportions unless a cure or treatment can be found, and if no cure or treatment, unless we can come up with adequate management and strategies to take care of these individuals.

Let me give you one very simple example: fever. The definition of "fever" in the elderly is not the same as in the younger individual, because the range of temperatures is different. There is not even the basic research to understand a simple thing such as the concept of what a fever in the elderly is. Research in this area to me appears to be essential, and clearly in the public interest, particularly as the aging population increases.

It is also important to know that there are presently stringent criteria in place to safeguard the incompetent individual. As a researcher I can tell you this is true. It is very difficult, because of the criteria that are already present, to have research proposals approved. So even more rigid restriction of research involving the incompetent elderly will be at the expense of those we seek to help.

I would like to recommend, as a researcher, that paragraph 1 of section 15 in Bill 109 be deleted or after careful review be amended and that Bill 108 be amended to provide an effective and efficient means of empowering substitute decision-makers to continue to give consent to the involvement of incapable persons in research.

**Dr Conn:** My name is David Conn. I am the head of the department of psychiatry at Baycrest. As a clinician, I have some serious concerns regarding Bill 109. I have a particular concern with regard to the potential delaying of treatment for elderly individuals who have been found to be incapable. Studies of nursing home residents suggest that between 50% and 80% suffer from some form of mental disorder. The most common form of mental disorder is dementia, of which the most common subtype is Alzheimer's disease. To date there have been no studies to determine what percentage of nursing home residents at this time are incompetent with respect to decision-making regarding their health care. Nevertheless, a figure of 50% would seem to be quite conservative.

Whereas the intent behind this bill to protect those individuals who are incapable is clearly a step forward, there is considerable danger that many nursing home residents and other elderly individuals in the community may suffer from needless delaying of important treatment, which might lead to pain, suffering and potentially to more serious illness.

It is my understanding that once this bill becomes law, if it is unchanged, a health practitioner shall not administer treatment until an advocate informs him or her that the person has received an explanation and has not indicated a wish to make an application to the board. There is an exception. The only exception occurs when the person is incapable, is likely to suffer serious bodily harm within 12 hours if treatment is not administered promptly and it is not reasonably possible to obtain a consent or refusal on the person's behalf.

My concern relates particularly to individuals who have severe dementia; that is, they are unlikely to understand the meaning of an advocate's explanation. Indeed, it

does state in subsection 10(3) that the advocate's explanation is sufficient, even if the person does not understand it. This would seem to be an unnecessary exercise that could potentially delay vital treatment. The individual's rights are not being protected if he or she is denied necessary treatment. The health practitioner would face a serious dilemma in trying to determine when an individual is likely to suffer from serious bodily harm.

The elderly are particularly vulnerable to even minor illnesses which can rapidly progress to more serious states. If an individual is suffering from pain, for example, under this act it would not be possible to administer analgesic medication. If the person had an upper respiratory tract infection or a urinary tract infection, it might be difficult to argue that these would be likely to cause serious bodily harm, although it might be an acute confusional state resulting from such an infection which temporarily renders the individual incompetent.

If an individual were depressed, perhaps withdrawn and non-communicative, treatment would be delayed. Nevertheless, it is clear that severe depression can ultimately cause major problems such as suicidal behaviour, decreased oral intake and eventually life-threatening deterioration.

We therefore recommend that Bill 109 be amended to eliminate unnecessary and potentially harmful delays in the treatment of incapable persons in non-emergency situations. A differential could be considered whereby various forms of treatment are categorized. Such stringent criteria as are contained in this act might be appropriate with reference, say, to surgical intervention, but seem to be excessive with regard to maintaining, adjusting or initiating routine medications.

Whereas it is recognized that in the ideal situation all such individuals would have an attorney for personal care or a guardian, the reality would appear to be that at the point when this act becomes law an enormous number of elderly individuals will not be in this position. This fact must be considered in order to prevent serious delays in treatment. I suppose one concern is just how long it will take to get an advocate. If we are talking here about 600 nursing homes and homes for the aged in Ontario with perhaps more than 50% of the individuals being incompetent, that is a lot of individuals who will be affected when this bill becomes enacted.

Finally, a few comments on assessors. We are somewhat disturbed by the lack of specific details in either Bill 108 or Bill 109 with regard to the definition of qualifications or training for assessors. The Weisstub report and the work of the Baycrest competency clinic have shown that the issue of competency is very complex. It seems to be critical that appropriate programs for the training and certification of assessors, who might include physicians and other health practitioners, be established. It should also be recognized that the issue of developing methods and criteria for assessing competency will require further investigation and research.

We would respectfully suggest that the Baycrest competency clinic, which is unique in Canada, should be considered as a primary resource in the implementation of ongoing educational and research programs with respect to

the determination of competency and the training of assessors. It is certainly critical that in order to avoid mass confusion more specific details should be worked out with regard to these qualifications prior to the passage of this legislation.

**Mr Chiarelli:** Thank you very much for your submissions. The comment was made that you would like to see some delay in this legislation and also some significant amendments. I think you ought to know that from our perspective on this side the government has no intention of delaying or redrafting this legislation. In fact, an NDP document yesterday showed that it is still one of its priorities and it intends to proceed with it. I had made on several occasions the suggestion that this legislation be withdrawn and then resubmitted to the committee so that it could be redrafted and looked at and restructured in a way that would be appropriate for a consensus of people who have come before this committee, most of whom, I might add, have very strong objections to the legislation in spite of some of the comments that most people are in support.

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Significant groups, experts, non-experts, have very significant concerns about this legislation. They also have a sense that in the long run or in the end the bill, when it comes forward, will address all these concerns. There are so many amendments which have been recommended and suggested on so many aspects of this legislation that to amend it in clause-by-clause would effectively redraft and rewrite the legislation.

I am very concerned about this legislation. What I have been doing with groups which have been coming in is asking them to work on the assumption that no amendments will be forthcoming because we have not seen any, and I am asking them what will happen in the field. "What will happen in your area of expertise, your area of care giving, if this legislation were to pass as is?"

We have had physicians coming here saying they will ignore it, we have had physician representatives of hospitals saying it would create chaos, we have had representatives for nursing homes saying that it will make their work almost impossible, and I have to assume that they are here with good intentions and that they really care for the people they serve and they care for the process. They are not here playing politics; they are here saying what they think actually will happen.

I am concerned that this government is not listening, that this is on its political agenda and it is going to proceed. I am hoping that if people like yourselves will say what will happen in the marketplace, in effect, if this bill passes as is, that maybe it will have an impact and maybe they will defer it, maybe they will redraft it or maybe they will look at another process. But quite frankly I am afraid they are going ahead with it, they are going to amend it as best they can to meet their political agenda in the next three or four months.

So could you tell me how you think this will work, as presently drafted, in your area of expertise?

**Dr Conn:** I think that with reference to Bill 109 and issues of consent to treatment, a lot will depend on how

rapidly individuals and their families are able to put into place powers of attorney for personal care or guardianship. From my experience, these processes do not occur overnight; it takes a lot of time and energy and legal advice and the courts sometimes, or in this case, I suppose, a much enlarged office of the public trustee and guardian to put into place a legal process whereby the health care practitioner will know who to go to to get consent.

My concern is that there will be thousands and thousands of individuals who will not have this process in place, and therefore it will be necessary to bring in advocates. I do not think we have any sense of what it would be like for advocates to come into nursing homes, for example. So much would depend on the design of that particular program. Hopefully the advocates would work with the health practitioners in the service of the individuals. There is a lot of concern, however, that the advocate's role might not be one of simply helping and assisting.

What is the individual health practitioner going to do when he is faced with an individual who is incompetent and who is suffering, who needs some sort of treatment or help? I do not know. Much will depend on the individual ethics, perhaps, of the practitioner. If they are going to abide by the letter of the law, then they may have to not treat someone who seems to need treatment.

**Mr Chiarelli:** Do you think there will be great variation in how this law is implemented and responded to?

**Dr Conn:** I think that is very possible, yes.

**Dr Stuss:** I would like to comment. It has taken a long time to get researchers interested in the problems of the elderly. It is just in the last five to 10 years that we have gotten to build up a certain corpus of young individuals, older individuals who are geared in understanding medical, psychological, psychiatric, sociological processes that occur both in normal and abnormal aging, "normal" meaning the issues of Alzheimer's disease.

There is a tremendous fear of brain drain. I am a director of a research institute. I have a very difficult time recruiting people because most of the people already want to go to the United States. One of the things I offer them is the ability to be involved in a place where we are truly concerned and the research is dedicated to understanding and improving care. It would be virtually impossible for me, I think, to build up a research institute and to attract individuals.

I cannot emphasize enough the concept, and I know we are talking strictly from the aging population, that we really do not understand even basic biological processes of normal aging. We just have not got the basic research done, things such as, as I said, fever, things such as variations in olfaction, just in smell and how these might affect things, not including aspects of disorders that might affect different kinds of types of dementias that do occur. My feeling is that we would have a very difficult time.

Without this kind of research we would have a real problem. Let me give you a practical issue that occurs. For example, an elderly patient may have a stroke in a very small area of the brain that would make this person appear very incompetent because he could not express his thoughts. What you would find, if you were able to evaluate

them properly, is that they are competent if it is presented to them and expressed properly.

This knowledge was advanced through research in brain behaviour type aspects. You would never be able to find individuals who would be able to make the adequate assessment unless you had somebody who is a specialized health professional. So I have tremendous concerns for the future of Ontario, not just in the short term but in the long term.

**Mr J. Wilson:** I very much appreciate the concerns you have brought forward in a very well-written brief. As Health critic for the Ontario PC party, there is one area, and I know it is hardly the most important concern, but I have heard a lot of the other ones before, and if it is any comfort, we will be bringing forward amendments to try to straighten out some of this stuff, particularly in the area of research.

On the redirection of long-term care, just your couple of paragraphs here on that, I would like to take the time to ask the parliamentary assistant what the relationship will be between the Advocacy Commission and the advocates and the service coordination agencies that have been and are being established under long-term care reform.

**Mr Wessinger:** I do not think I could really answer that question because we have not yet determined what the role of the advocates is going to be. We are still in the—I think you would have to ask the—

**Mr Chiarelli:** You have got to be kidding me. You are bringing forward this legislation and you do not even know what the role of the advocates is going to be? What an admission.

**Mr Wessinger:** I am just suggesting that it is a matter for the parliamentary assistant of Citizenship to answer with respect to what role the advocates may or may not play. But I would suggest that the whole concept of the act is for the Advocacy Commission to determine the role of the advocates and the recommendations with respect to this role. It is an evolving process, and I will just turn it over to the parliamentary assistant to confirm that.

**Mr Malkowski:** I would like to refer this to counsel to clarify this point.

**Ms Spinks:** With respect to the Advocacy Act, I think it does set out in section 7 what the role of the advocate will be in providing systemic advocacy and in providing advocacy to individuals who are vulnerable. I do not think that there will be a distinction in terms of vulnerability. If the person is vulnerable and is involved in some kind of a project or facility related to long-term care, that will not make any distinction. If they are vulnerable, they have access to the services.

**Mr J. Wilson:** The point here is it does sound as if, especially when you put it in legislation, this Advocacy Commission is going to be politically active, advocating systemic advocacy, and it has a bias. It is supposed to be arm's length from the government, but it is stacked with vulnerable people. They raise a very good point that has not been raised before about also having these 40 coordinating agencies under long-term care.

It makes me suspicious with the answer from the parliamentary assistant to the Minister of Health, like Mr Chiarelli's suspicion, that this is just a politically driven

piece of legislation. It does not appear that the government and the various ministries really know what each is doing.

**Mr Wessenger:** With respect, Mr Wilson, I think it is very clear that the role of the advocate with respect to the Consent to Treatment Act is only as a rights adviser, and that is the only aspect which deals with our legislation.

**Mr J. Wilson:** I sure hope you are right, but I have a feeling you do not know what you are doing.

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**Ms Carter:** I think first of all I will just add to what was said following the previous question, that long-term care is still out for discussion. That is not cut and dried either, so I think the questions may be a little bit premature.

I want to address Dr Greengarten's condemnation of advocacy, and I do personally have special concern for the elderly. Obviously it is not needed when family and care givers are supportive, and somewhere in your brief you do acknowledge that there are occasions when this is not the case. Sometimes family and care givers can be guilty of neglect and exploitation or not regarding the wishes of the vulnerable person.

How will evidence of abuse come forward if the abused person cannot express himself and does not have access to an impartial person? You say that you think the powers of entrance accorded to the advocate are excessive, but how else can this kind of abuse be uncovered and dealt with?

**Dr Greengarten:** Thank you for raising that point. As we know, probably 80% to 90%, maybe even over 90%, of care for older adults is provided by their families, and there is a small proportion of situations where there is abuse that occurs and we believe that abuse should be addressed aggressively. What we have concern about is the universal application of a system when the problems, we believe, are an exception rather than the rule.

We do believe that these situations should be identified for the authorities, and one approach we have discussed is perhaps to require health care and social service providers, as well as others in the community, to report evidence of abuse—and I am referring to abuse in the broadest sense—to appropriate authorities. This type of requirement, which exists with respect to child protection legislation, for example, does not exist with respect to the elderly. We believe that this type of approach would identify those specific situations where abuse is occurring and we believe that in most of these cases, even where abuse is occurring, it is not because there are evil people, it is because there are care givers, mostly family care givers, who are under extreme pressure to provide care for their loved ones. The abuse that results is abuse which occurs growing out of that caregiving relationship. Fundamentally, we seek a system which supports the family care giver and does not intrude and undermine it.

**Ms Carter:** But we feel that is what advocacy is offering, and you were suggesting that this kind of thing should go before the courts. I think we are hoping to avoid that. Sometimes there have been tragedies of neglect and abuse such as Cedar Glen, and coroners and juries have called for an advocacy service. Do you think this is wrong, for coroners, juries or O'Sullivan in his report to call for advocacy?

**Dr Greengarten:** I think the difference is whether we have a universal system which is applicable to all elderly, potentially, and which gives case-finding powers or fishing expedition powers to advocates, as opposed to a system which addresses identified problems of abuse which have been identified by health care professionals or families or others and which we believe will come to light if professionals and others are required by law to report such incidences of abuse.

We definitely believe that situations of abuse should be investigated by properly trained authorities. However, the difficulty is that this legislation as it is presented, at least as we understand it, would create a network of people to investigate situations where there is absolutely no evidence of abuse, where probably the problem is one of differences among family members, for example.

We deal on the front lines with families every day and with older people, and the issues are very difficult. The decision to care for an older person, to institutionalize an older person or not to institutionalize an older person, is a very traumatic one and one that tears families apart day in and day out. It is very common, in fact it is the rule, as far as our experience goes, that where you have, for example, an older person and two or three children, there are often disagreements among them about what the best course of action is to follow. If one of these children or an older person were to launch a formal complaint or to seek an advocate to intervene, we are concerned that this would not be the best approach, and this is not what the advocacy system is intended to do. So that is what our concern is.

**Ms Carter:** It seems to me that this is the least intrusive type of follow-up, but I would like to call on Mr Fram to comment.

**Mr Fram:** On the issue of abuse, one of the key concerns of organizations like the Advocacy Centre for the Elderly is that in the jurisdictions where there is mandatory reporting, serious problems of institutionalization are a result.

As you are probably aware, Bill 108 provides that the public guardian and trustee is given authority and indeed a duty to investigate allegations of abuse when serious illness or injury, deprivation of liberty or personal security require prompt action. I think that is the aspect you are addressing your mind to, and I think there is general consensus that this is probably the most sensitive approach to avoiding institutionalization in situations where there are allegations of abuse.

**Dr Greengarten:** I am sorry. I am not clear what you are saying. In the case of older adults, are you suggesting that the concern is that abuse will lead to institutionalization?

**Mr Fram:** That legislation which focuses on adult abuse in general leads to institutionalization, legislation like that found in the US. It is found that the strongest legislation dealing directly with the issue of abuse is found in those places with the fewest services to support family, to support the working out, the mediation of problems, the keeping of people in their homes and so forth, the background of service. It seems easier for a government to put forward legislation that on its face appears to address an issue of abuse, gives the authorities, the equivalent of

children's aid associations etc, authority to come in, move the person to a hospital facility or place of safe keeping, from which they do not often emerge. That seems to be the pattern where abuse legislation is the focus.

There are two aspects to the Bill 108 approach which are important. First of all, it does not require that all abuse of adults—adults by and large, as you know very well, can maintain their own integrity and decision-making functions to very great ages. It does not focus on the issue of ageism at all, which is a problem in our society. Just because you are old does not mean you are incapable. This focuses on the question of mental capacity and risk, and I think this is a model we believe will achieve the least intrusion and the best result.

My concern was focusing on abuse legislation, which then leads to other things like concern for avoiding risk and doing all sorts of assessments which are predictive of risk, which so far have not gotten beyond 50-50 in terms of predictability in family relations. Why I wanted to speak was because I have a great concern that the committee might be directed to thinking about abuse legislation.

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**Mr Greengarten:** Certainly you have far greater knowledge of these other forms of legislation than we do and we would not pretend to know that. What we do believe, though, is that this is a highly intrusive system that is proposed.

**Mr Fram:** On the issue of intrusiveness, if I can pick—

**The Chair:** Thank you, Mr Fram, we have to move along now. Mr Wessinger, very shortly.

**Mr Wessinger:** I would like to ask you with respect to the matter of research on incapable persons, are you saying you want it to be ensured that the existing law remains in effect with respect to that aspect?

**Dr Stuss:** Probably. I am not sure if I know exactly all the details of the existing law. I do know that in practice, through the University of Toronto and ourselves, we have considerable safeguards at the present time and it seems to me that the law, as I read it at present, goes far beyond the safeguards that are presently available, which seem to be—

**Mr Wessinger:** I would just like to comment on that. The clear intent of the bill is not to change the existing law at all. In fact, we have advice from our counsel that the legislation does not at all affect the existing law with respect to doing research on incapable persons. If any clarification is needed in that regard, I am sure that clarification will be done. But just to follow up on this question, I would like to ask you, is research presently done on incapable persons?

**Dr Stuss:** At the present time? Certain types, yes.

**Mr Wessinger:** I assume you understand the law that only therapeutic research may be done on incapable persons?

**Dr Stuss:** Yes.

**Mr Wessinger:** So you would say all research that is being done falls under the category of therapeutic research?

**Dr Stuss:** That is logic, is it not? If some, if all—I am not sure if I followed that through—

**Mr Wessinger:** I am just asking, can you assure me that in your experience all research falls within the legal category? Is all research being done presently legal, in your opinion?

**Dr Stuss:** Certainly in our institution, yes. We certainly make every effort, and we have a legal expert who heads up our ethics committee to ensure that occurs.

**Mr Wessinger:** Are you a hospital under the Public Hospitals Act?

**Dr Stuss:** Part of our facility is, yes.

**Mr Wessinger:** So your research is done under the authority of the Public Hospitals Act, which would be to obtain the consent of the substitute decision-maker under that act. Is that correct?

**Dr Stuss:** Yes.

**Mr Wessinger:** I was wondering if any of you have read the comments of the Minister of Health with respect to what areas of Bill 109 she is looking at. Have any of you had any information? I would like to indicate to you that the minister has indicated that the emergency powers provisions are being looked at, in particular, the provision with respect to the 12 hours and also with respect to the matter of relief of severe pain. I would like to assure you that those are certainly under consideration.

**The Chair:** A brief comment, Mr Chiarelli.

**Mr Chiarelli:** Just very briefly, the comment was made with respect to the principle of advocacy by Mrs Carter. I think virtually every presenter who has come here has supported the principle of advocacy, but the principle of advocacy can have a wide range of possibilities in legislation or non-legislation. I think we are not arguing the principle of advocacy in any way, shape or form; we are arguing the particular provisions of this bill as to how those principles will be implemented. I think it is very important to make that distinction. I think very few of us will disagree with what Sean O'Sullivan had to say, but it is obvious that a lot of people disagree with this legislation.

**The Chair:** Dr Greengarten, Dr Stuss and Dr Conn, on behalf of this committee I would like to thank you for taking the time out this afternoon and coming and giving us your presentation.

**Dr Greengarten:** Thank you very much. Good luck.

STANLEY WORONKO

**The Chair:** I would like to call forward our next presenter, Stan Woronko. Good afternoon. As you know, you will be given half an hour for your presentation. The committee would appreciate it if you would hold your remarks to about 15 minutes to allow some time for questions and answers. As soon as you are comfortable, please identify yourself for the record and then proceed.

**Mr Woronko:** I am Stan Woronko. I am a parent of a vulnerable person and am here not representing any group or association. I am merely here to voice our family's concerns and to voice our support for the adoption of the Advocacy Act.

By way of background, I want to tell you a bit about my daughter. She is 20 years old now. She suffered some

severe reactions to her vaccinations as an infant and she suffered brain damage as a result, so this slowed down her development. Today she is 20 years old. She does not speak; she does not use language to communicate. She uses two hand signs we have taught her, and uses those reliably. But in general she communicates by sort of inventing her own system. She takes us by the hand to different parts of the house if she wants something, for example.

The point of all this is that we have had a lot of experience in trying to make Katherine belong to the real world. Some of those challenges have been with her training, and we have had more than our share of behaviour management programs and learning how to use positive reinforcement and all those things. Those were challenges, but not the formidable challenges. The formidable challenges have to do with dealing with the institutions of our society, the bureaucracies and the attitudes.

These barriers we faced started from a very early age. For example, when she was still an infant we received advice from health practitioners to place her in an institution. This would certainly have made our life simpler, in some ways much simpler, but at the same time she would have been forgotten. We doubt anyone else in the world would have paid attention to her. Such solutions are not really solutions.

The other examples we faced with the health system are cases where we were denied certain forms of treatment for her because of her prognosis. An example of that is that when she was three years old and still not able to walk, a neurologist in a famous institution here in Toronto refused to prescribe physiotherapy services because his prediction was that she would never be able to walk, so it would be a waste of time. Well, she did learn to walk when she reached the age of six.

I guess the most strenuous obstacles we faced were in dealing with school boards and educational systems. In most school boards in Ontario, the general practice is to segregate students who have exceptionalities, and it makes it very hard to integrate them into society.

The point of these examples is that when bureaucracies, institutions and professionals, and sometimes even parents, purport to do something on behalf of vulnerable persons, they are often proposing actions or decisions which really are meant to make their lives easier and to make the systems easier to administer rather than to serve the interests of the vulnerable persons. Examples such as the use of cattle prods or segregation clearly show that there are certainly situations where the best interests of individuals who are vulnerable are not served well by bureaucracies and institutions.

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For these reasons, I strongly support the Advocacy Act. I recognize that the way it will be implemented is not at all clear, and I will address that within my recommendations. Nevertheless, it is definitely needed and is a step in the right direction.

A few of the concerns which I would like to raise are as follows. One, I would recommend that the act apply to persons of any age. Children's rights need to be protected

as well. Sometimes parents, though they try to be advocates, get burned out because of the pressures of their family situations. They find it very difficult to face powerful bureaucracies and they could use support from an advocacy system. This support could be in the form of education or simply occasional support or advice. Nevertheless, children's rights are subject to abuse as well as adults' rights.

The second recommendation is that the schedule of facilities covered by this act should include facilities governed by the Education Act and by the colleges and universities act, because education is fundamental. It is a very fundamental right, and the quality of education that people receive, particularly in the case of people who are vulnerable, may have a very strong long-term impact on their lives. Education, being that it forms such an important foundation for life, is crucial.

The right to look into situations that arise in schools, for example, is very important. One example is a case where one year our daughter, through our pressure, was integrated into a regular high school and some regular classes, and she needed the support of educational assistance. On a couple of occasions it was reported to us by her peers, who were acting as natural advocates in this instance, that the educational assistants were being abusive and putting undue pressure on her. For example, she was afraid to go up and down steps. They would get very impatient and angry at her if she did not do it fast enough. So instances like this where a person is being subjected to some form of abuse—our daughter was getting very nervous after a while and was very apprehensive of anyone being around her—need to be looked at.

In our daughter's case, she was not herself able to communicate to us what was happening to her. We were lucky that she had friends, natural friends, who were able to report this to us; otherwise, we would never even have known about it. Nevertheless, even though we did get some information like that, it was very hard to deal with the school system because it is a very closed system. Everything goes on behind closed doors. You have the opportunity to report to the principal any abuses, but what is done about it is very hard to verify.

The third point I would like to raise is that with regard to encouragement of advocacy by organizations and within community organizations, I think the act should recognize that sometimes a conflict of interest could develop. That should be addressed, that some organizations provide services, and advocates who work for those organizations might not be effective advocates with respect to the quality of those particular services.

Another example would be that where an organization is funded by government and that same ministry is doing something which is not recognizing the rights of an individual, it might be harder for an advocate to deal effectively with that particular ministry. So I do not think we should prevent organizations from having advocates, but I think the situation of conflict of interest should be identified and addressed.

The fourth recommendation is that we not stress too much the academic qualifications of advocates, but more their basic qualifications in terms of abilities, interpersonal

skills, value systems and so on. I would not like to see a system where qualified people are excluded simply because they do not have a very high degree of formal academic qualification.

I also recommend that a code of ethics be developed, and this could be part of the function of the commission.

Fifth, I want to stress the role that natural advocates can play. To be an effective advocate, one has to know the person for whom one is advocating. I do not believe paid advocates can do the job entirely on their own. Their contribution could be very strong in the area of knowing the system, knowing the laws and having a broad range of experience; however, knowing the person is very important. Some people are lucky enough to have friends and relatives who are good natural advocates, or potentially good natural advocates, and one system should not replace the other. They should be mutually supportive. This would not only be more effective, but would also provide some leverage in terms of the costs of running such a system.

The act does not spell out how advocacy would be promoted by community agencies or within the more natural settings. I believe there is some reference to it in section 1, but I think it could be spelled out a bit more explicitly. In particular, for example, I would visualize having courses for volunteers, training sessions made available to become more familiar with the laws, learn how to negotiate, learn self-assertiveness and so on.

By the way, self-advocacy would also be promoted this way. Some people who are vulnerable—indeed, anyone—may not be an effective self-advocate in every area. It is possible that some people may need help when it comes to advocacy in certain areas but that in other areas they may be able to handle it on their own, and I think that should be encouraged.

Finally, in closing, I would like to bring to your attention a poem on the final page of my brief. I do not necessarily want you to read it now, but do read it. I think it evokes very strongly why we need an advocacy system, and does this better than what we could do with any legal or academic analysis. Thank you.

**Mr Chiarelli:** Mr Woronko, thank you very much for your comments, particularly your suggestions and recommendations. I think virtually every one of them deserves consideration by this committee if it is going to proceed with the legislation.

I want to ask kind of a hypothetical question of you. It has more to do with Bill 109. Let's say Katherine were to find herself in the emergency room of a hospital or at some clinic or before a medical practitioner because of some illness or injury not related to her disability; she just needed medical treatment, and this illness came upon her or she was injured, unknown to you. If somebody brought her to the hospital by ambulance or what have you and there was an issue on the part of a physician as to some treatment that was necessary for Katherine, how do you foresee the communication and the decision-making taking place under those circumstances?

**Mr Woronko:** I would assume, first of all, if contact could not be successfully established, that the attending

physician would have the prerogative and the right to make a professional decision on what is in the patient's best interests.

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**Mr Chiarelli:** Would Katherine be able to communicate?

**Mr Woronko:** No, she would not. I think it would fall in a similar category to if a person was injured and unconscious and the doctor had to make a decision about what to do about it.

**Mr Chiarelli:** The reason I am asking that question hypothetically is section 10 in Bill 109. I will read it for you so you will get an idea of what we are talking about here, because I am concerned about parents and family members, such as yourself, under these circumstances with the provisions of Bill 109. It says:

"When a health practitioner finds that a person who is 16 years of age or more is incapable with respect to a treatment, the health practitioner shall,

"(a) Advise the person of the finding, unless the person is unconscious."

The health practitioner would have to try to advise Katherine.

"(b) Give the person a written notice (which may be in the prescribed form), unless the person is unconscious, indicating that the person is entitled to meet with an advocate and is entitled to make an application to the board."

That written instruction would have to be given or shown to Katherine, whether it is appropriate or not. It is a requirement in law.

"(c) Notify an advocate of the finding."

I asked the question last week, most particularly. I say, therefore, there is a legal obligation under those circumstances, before treatment is given, that an advocate must be notified, and the advocate must then come and advise Katherine of her rights before treatment can be given. I asked specifically, "Is there a legal obligation to try to contact a parent?" and the answer was no.

I am concerned about the advocacy provisions of Bill 109 as it applies to people like Katherine and many others, and I think this committee has to seriously reconsider how section 10 of Bill 109 operates; at the very least, perhaps, write in a provision that says that the medical practitioner, in addition to notifying an advocate, has a legal obligation to endeavour to find out if there are family members, where they are, and also to notify them of the circumstances. At the very least, you will have two things coming together at the hospital or in the emergency room; you would have an advocate coming as well as a parent.

In many cases you may find that the medical practitioner would automatically and out of courtesy notify a parent or a relative to come to the hospital because there is some kind of emergency, but that is not now in the law. The only legal requirement is to notify a third person, a stranger, an advocate, to come and advise Katherine. Would Katherine be competent to understand what an advocate might be communicating to her?

**Mr Woronko:** No. In reference to this question, is that the section of the act that lists a priority list of people who may make the decision?

**Mr Chiarelli:** No.

**Mr Woronko:** That is another one, okay.

**Mr Chiarelli:** If I can be very clear, you have a physician in an emergency room—

**Mr Woronko:** Yes, I understand.

**Mr Chiarelli:** —and Katherine is there, and he is deeming that he cannot receive instructions for treatment from Katherine. The law says his legal obligation is to notify an advocate, and it stops there.

**Mr Woronko:** My suggestion in this circumstance would be that if it is an emergency that cannot wait for that advocate to come, that my daughter or the person's health would be in serious jeopardy if this contact could not be made in time, there should be a way for the physician to go forward and do the treatment, just as he would do for an unconscious person.

**Mr Chiarelli:** There is a way, and there are provisions in here for the physician's proceeding in certain emergency circumstances, and we have heard that they are going to be proposing some changes to that. But failing that, and you take it the next step, if the treatment can be deferred for a short while, it is not an emergency, there is still a legal obligation for the medical practitioner to get in touch with an advocate and not to get in touch with the parent. How do you feel about that?

**Mr Woronko:** I guess I misunderstood, because I did not address that bill, so I do not know very much about it. I was under the impression that there was a priority list, and the parents came before the advocate if the person was not under a guardianship.

**Mr Chiarelli:** That is a totally separate issue in a different context.

**Mr Woronko:** Okay. In this instance, I would prefer that the doctor be in touch with the natural guardians, the parents or the family, the relatives of the person if those are known, if there is some information or identification. That would be the first line.

**Mrs Cunningham:** Thank you for appearing before the committee today to give us some good advice. I wonder if you had a chance to take a look at Bill 109 or Bill 108.

**Mr Woronko:** Just a bit. I get lost in the intricacies of the guardianship.

**Mrs Cunningham:** I think it is one of the problems that the government should be looking at. As parents, it is very difficult to know even which ministry to address. Bill 109 is the Minister of Health, Bill 108 is the Attorney General and Bill 74 is the Minister of Citizenship.

I too am a parent of what would be considered a vulnerable child and have some interest in this legislation and find it particularly confusing. I hope the government will take that under advisement, even if it means a total redrafting of the intent. I think the intent is admirable; I just find it extremely confusing. I would ask you if you will take a look, as a parent—we do not often get parents before this

committee—at Bills 108 and 109. My colleague mentioned section 10 of Bill 108. Is that right, Bob?

**Mr Chiarelli:** Bill 109.

**Mrs Cunningham:** Bill 109, and the other one there would be section 16. If you would do that, we would appreciate it, and if you have any difficulty getting these documents, we will be happy to provide them to you.

**Mr Woronko:** I have a copy. I will do that.

**Ms Carter:** Thank you for your very constructive presentation. You do seem to have entered into the spirit of the act as we see it. Do you agree with the consumer-based control of the advocacy system that is outlined in the bill? I am sure you are aware of section 15, where we list the different groups that need to be represented on the body that appoints the commission. Also, the commission itself is envisaged as being at arm's length from government and having a very independent role.

**Mr Woronko:** I think that is essential, that people who are vulnerable have a strong voice in the way things will be run, because they are the ones facing the situations on a daily basis and are more aware of what is required. If somebody else stepped in to do it for them, then it would be another case of substitute decision-making.

I have some slight concerns about certain organizations that act on behalf of persons with disabilities. Some organizations are service-oriented rather than advocacy-oriented. They may tend to be defensive and protective rather than progressive. So there is a danger there. Some organizations are more geared to raising money for charity, but I do not think one can draw a sharp line. One has to accept these realities but be aware of them.

**Ms Carter:** Yes. The qualifications of advocates will be decided by the commission, so your point 4 will be dealt with at that level.

Some parents have come before us saying that as parents of a younger child, they were in control of the situation, but when the child becomes an adult—in your case, you say your daughter is 20—they are not included in the process if, for example, their child was in an institution. Can you comment on that?

**Mr Woronko:** This is the point I try to make in my fifth recommendation. I think the advocacy system should try to be a mutually supportive system to try to take advantage of natural advocates. If parents are there and they are interested, they should be invited to be involved and to work things out cooperatively.

**Ms Carter:** Of course, we did not envisage children as coming under this, because certainly, under a certain age, they are not able to express opinions that should be taken into account in the way that those around a person should. But you seem to be suggesting—and you are the not the first presenter to suggest this—that in a sense, an advocate could help the parents of children in this position because they do carry a very heavy burden and they need a little help and guidance.

**Mr Woronko:** Definitely. First of all, parents may have extraordinary demands on them simply because of the day-to-day situation in the home and whatever. Then,

having to deal in a first-time acquaintance with some very unique obstacles that one did not expect with some powerful bureaucracy can be very difficult, and many parents just simply give up and just accept what is available, and their children suffer.

**Mr Wessenger:** Thank you for your presentation. I just thought I would try to clarify something with respect to the Consent to Treatment Act. I am of the opinion that, really, in your particular situation that act would not interfere with the communication between the medical practitioner and yourself, because what the act provides in section 10 is that the advocate meets with the person who has been determined to be incapable of making a decision. It is only if that person has indicated a wish to make an application to the board to dispute the finding of incapacity—and as you have described your daughter, she would not be able to do that. That would immediately kick in section 16, which sets out the list of persons able to receive treatment. Of course, the parent is on that list, and the only person who would have higher priority is a spouse or child. So you would be communicated with and would be the person to give the consent with respect to that treatment. Section 22, on the other hand, does provide for emergency treatment. So I just suggest, in your situation, that I think the legislation would not interfere with that aspect.

**The Chair:** Mr Woronko, on behalf of the committee, I would like to thank you for taking the time out this afternoon and coming and giving us your presentation.

Our next presenters needs a few minutes to catch their breath, so this committee stands recessed until 3:30.

The committee recessed at 1514.

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#### YORK SUPPORT SERVICES NETWORK

**The Chair:** I now call for our next presenters, from the York Support Services Network. Good afternoon. Just to remind you, you will be given a half-hour for your presentation. The committee would appreciate it if you would limit your remarks to about 15 minutes, to allow time for questions and comments from each of the caucuses. Please identify yourselves for the record.

**Ms Hubbert:** Good afternoon. My name is Penny Hubbert and I am the president of the board of York Support Services Network.

**Ms Paul:** I am Louise Paul and I am the executive director with the agency.

**Ms Hirstwood:** My name is Karen Hirstwood and I am the program manager with the agency.

**Ms Hubbert:** York Support Services Network believes in the dignity, individuality and independence of all persons. The agency promotes, facilitates and supports community participation for individuals with special needs and their families through the provision of case management, advocacy and community development activities. We have provided case management, social advocacy and community development services within the regional municipality of York for the past 10 years, so we have been around for a while. Currently we are serving adults with serious psychiatric conditions, adults and children who

have developmental handicaps and their respective families. Services are offered through a variety of programs that we provide, including the adult protective service worker program.

The comments we are going to make today are based on our experience in service delivery for the populations we serve. We will focus specifically on Bill 74, An Act respecting the Provision of Advocacy Services to Vulnerable Persons, and Bill 108, An Act to provide for the making of Decisions on behalf of Adults concerning the Management of their Property and concerning their Personal Care. Consideration has been given to how these bills interconnect with Bill 109, An Act respecting Consent to Treatment, and other existing legislation.

First, we would like to acknowledge this government's intention to protect the rights of vulnerable people, and we certainly applaud its efforts thus far. Generally our agency views this innovative legislation as a positive step and one that is long overdue. Our comments and concerns throughout this document are based on our experience in the delivery of case management, social advocacy and community development services over the past 10 years.

From our perspective, we recognize that most of what is proposed will codify the common law as it now exists. It is particularly important that the premise that an individual may be considered incompetent for specific tasks but not necessarily globally incompetent be codified. We support the premise that competence is assumed unless otherwise indicated. The following recommendations are based on our interpretation of the proposed legislation.

We will address the following: public education, training for advocates, capacity to provide rights advocacy and case advocacy, community development, financial resources, the role of the public trustee and a few operational issues. The recommendations are as follows.

Our first recommendation is that given the complexity of the various bills which comprise the new legislation, and their interconnection with existing legislation, a comprehensive public education campaign is required for vulnerable persons, their families, service providers and the community so that they are informed.

Our second recommendation is that since advocates will come from varied backgrounds and perspectives and will be required to provide services in a broad range of situations, the commission recognize training as a crucial component of successful implementation and take steps to ensure appropriate training occurs. We see this as key.

Our third recommendation is that the commission needs to be aware that many rights-related issues in community settings can be very complex and require long-term involvement to reach resolution. Having provided case management services to vulnerable populations for 10 years, we are well experienced with how long, involved and complex some of these situations can be. This fact needs to be taken into account in the commission's determination of the advocates' responsibilities in case advocacy versus their role in rights advocacy, which in our understanding is short-term.

Our fourth recommendation is that given that the involvement of an advocate will potentially increase access to resources by a vulnerable person, there needs to be an

ongoing commitment to the community development component of the legislation to address unmet needs.

Our fifth recommendation is that since the involvement of the advocate potentially creates a greater vulnerability for some individuals, there should be a commitment to the provision of financial resources to provide for an alternative safe environment when necessary.

Our sixth recommendation is that the present structure and resources of the public trustee's office be restructured to ensure that office can respond quickly to issues and with the flexibility outlined in Bill 108.

Our seventh recommendation is that through the development of policies and procedures by the commission, the operational issues of authority and liability of advocates be addressed.

The rationales for the recommendations are as follows. These comments, again, are based on York Support Services Network's experience in the delivery of case management, social advocacy and community development services.

**Public education:** Given the complexity of the various bills which comprise the new legislation and their interconnection with existing legislation, a comprehensive public education campaign is required for vulnerable persons, their families, service providers and the community.

Many community-parent groups, such as Friends of Schizophrenics, are strongly opposed to the advocacy legislation based on their understanding or misunderstanding of the act. For example, during a presentation sponsored by our agency in May 1991 the Honourable Elaine Ziemba, Minister of Citizenship with responsibility for disability issues, was questioned by a parent of an adult who has a diagnosis of chronic schizophrenia. The question centred on the right to entry for advocates that the act provides. The parent had interpreted the legislation to mean that, based on right of entry, an advocate could enter his home at any time. The legislation clearly provides the opportunity for the commission to impose limits on the right of entry.

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This particular parent's concern was that during the times when his son is not as well as at other times, he could present any kind of scenario for someone who might not understand the situation and, based on that, would have entry to come into the home and start judging the situation.

Individuals, families, the community service providers and local government must be made aware that the Advocacy Act does not create or extend new rights to vulnerable people, but rather ensures that an individual's rights and preferences are articulated. The act is designed to create opportunities for people to take control of their lives and transform the conditions they live in.

A comprehensive public education program regarding both the existing legislation—the Mental Health Act—and the proposed legislation is an essential step in the successful implementation of this act. Ideally, public education will occur at many levels in a variety of ways so that we can be sure to reach the different groups in the community. As part of that education, I think people are quite surprised

to find out that vulnerable adults do not have existing rights assured them.

**Training for advocates:** Since advocates will come from varied backgrounds and perspectives and will be required to provide services in a broad range of situations, the commission needs to recognize training as a crucial component of successful implementation and take steps to ensure that appropriate, adequate and ongoing training occurs.

Presumably advocates will come from varied backgrounds and perspectives and will be required to provide service in a very wide variety of situations. For example, given the rights of entry the legislation provides, an advocate needs to be knowledgeable about illnesses such as schizophrenia. During an acute phase of this illness an individual may make claims that are based only in the paranoia caused by the illness and not in fact. An advocate needs to be able to discern the difference between fact and symptoms of an illness. It is conceivable that in the same day the advocate would also be called upon to provide rights advice in a landlord-tenant situation. The training of advocates is a crucial step in the public education process.

**Capacity of advocates to do rights advocacy and case advocacy:** The commission needs to be aware that many rights-related issues in community settings can be very complex and require long-term involvement to reach resolution. This fact needs to be taken into account in the commission's determination of the advocates' responsibilities in case advocacy versus their role in rights advocacy.

York Support Services Network supports this statement in principle. However, our experience indicates that individuals whose rights have been violated or who have unmet needs often require a longer-term involvement. This involvement is generally based on a trusting relationship and provides support and skill development enabling the individual to enhance his or her own ability for self-representation. This need is often met through the provision of case management services. Our concern is that the Advocacy Commission will not have the resources to meet the volume of cases or the time to remain involved in the situations which require longer-term involvement.

For example, during the past year York Support Services Network provided service for approximately 800 people. There are an additional 300 individuals on the wait list for service. Of these 800, approximately 560, or 70%, require advocacy services. These figures represent only one region of the province and two populations which comprise a very small portion of Ontario's vulnerable citizens. In one situation, which is not unusual, it took over one year to identify the individual's issues and complete the interventions necessary to resolve the issues.

**Community development:** Given that the involvement of an advocate will potentially increase access to resources by vulnerable persons, there needs to be ongoing commitment to the community development component of the legislation to address unmet needs.

The Advocacy Act states that the commission will ensure that community development strategies are applied in the provision of advocacy services. However, the act makes no further references to community development. Again, based on our experience and on the literature available on

the subject, the involvement of an advocate will facilitate access to community resources. Therefore, an increased and ongoing commitment to the development of community resources is essential.

**Financial resources:** Since the involvement of the advocate potentially creates a greater vulnerability for some individuals, that there be a commitment to the provision of financial resources to provide for a safe alternative environment when necessary.

The legislation provides the advocate with the right of entry but falls short in that it does not provide the resources necessary to ensure appropriate follow-up, such as providing an alternative safe environment, if that is required.

Once an advocate becomes involved, an individual may become even more vulnerable. For example, the maritime provinces have legislation in place which requires mandatory reporting of elder abuse. However, once the abuse is reported, there are not sufficient resources to provide an alternative safe environment. As such, the abuse is reported but the legislation does not specify who is responsible for follow-up, and the resources are not there to provide adequate follow-up. The result is that the abused elderly are more vulnerable than before the advocate got involved.

Bill 74 clearly provides for right of entry where there are reasonable grounds to believe that the health or safety of a vulnerable person is in danger. However, it provides no authority regarding the provision of resources, financial or otherwise, should a vulnerable person need to be removed from a specific environment. In our opinion, this is a critical issue. Advocates must have access to financial resources to carry out their responsibilities.

**The role of the public trustee:** That the present structure and resources of the public trustee's office be restructured to ensure that the office can respond quickly to issues, and with the flexibility outlined in Bill 108.

A new residential placement was arranged for a woman who previously resided in a home for special care. She was in a very vulnerable position. Once a new placement had been obtained for her, a follow-up period of a year was required to negotiate with the public trustee's office to establish the flow of funds which she was entitled to. At one point, the delay caused by this situation put the new placement in jeopardy.

YSSN's experience with the public trustee's office is consistent, unfortunately, with the example above. Lack of resources and the current structure have been cited as reasons for delays in responding to both financial situations and instances where substitute decision-making has been required. Bill 108 provides time frames by which specific steps in a process must take place. It is our concern that the present structure of the public trustee's office will not enable this to happen.

**Operational issues:** That through the development of policies and procedures by the commission, the operational issues of authority and liability of advocates will be addressed. Our final three areas of concern centre on operational issues.

It is our understanding that the Advocacy Act will govern all advocates. If so, how will authority be maintained in terms of volunteer advocates or those not employed by the

commission? The act does not specify who has authority in these instances.

In addition, a major area of concern is the exemption from personal liability for members of the commission and paid or volunteer advocates. Clarification is needed regarding what recourse is available to a vulnerable person if an advocate neglects or defaults in the execution of his or her duties. There is irony in the fact that the advocate's role throughout Bill 74 and the related bills, 108 and 109, is clearly that of a rights adviser and is instruction-based, yet the advocate is exempt from personal liability. These operational concerns must be addressed by the commission in the development of policies and procedures for the advocacy system.

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Our final concern relates to the potential transfer of the adult protective service worker program from the Ministry of Community and Social Services to the Ministry of Citizenship. Our agency recognizes that a decision regarding this has yet to be reached. However, given the importance of the combined advocacy and case management service provided by the APSW program, we feel that we must address our concerns to this committee.

Case management is an integral part of the APSW program and is essential in the service delivery system for individuals who have a developmental handicap. Equally important is the advocacy service provided by the APSW. Combining the case management and advocacy role has worked well historically and continues to work well in many areas across the province. It is the opinion of YSSN that the information put forward by the Adult Protective Services Association of Ontario may not represent the consensus of all adult protective service workers or their sponsoring agencies.

We feel that further consultation with APSW workers and sponsoring agencies is needed before a decision regarding the transfer is reached. We are concerned that if the transfer of this program occurs, the combined role would be eroded and an essential part of the service delivery system would be lost. It is difficult for us to envisage a scenario where the APSW role of combined case management and advocacy are not intact.

We would like to reiterate that our agency views this legislation as a positive step in the protection of the rights of vulnerable people. We appreciate the opportunity to express our concerns to this committee. At this time, we will be pleased to answer any questions you have on these issues.

**The Chair:** Thank you. Questions and comments? Mr Chiarelli.

**Mr Chiarelli:** Thank you very much for your submission. I appreciate your comments and the experience from which it comes.

I am particularly interested in your recommendation 5 with respect to financial resources. Members of this committee have raised the issue of what this program and what this initiative would cost, and we have not been able to get an indication, other than it has not been costed out. You have raised a secondary or resulting cost factor, in terms of follow-up residences and so on and so forth.

I think Mr Fram indicated earlier that in cases where there was specific legislation governing elder abuse etc, it seemed to result in more institutionalization. I am not sure he is making the same point you are making. What you are basically saying is that if you are going to have advocates going out and finding where there is abuse of various types, you are going to have to have a solution for that. I think the principle of doing that is excellent. It ought to be done and people ought to be protected, but I also think that people have to act responsibly in the process. You and I both know what a budget crunch this government is facing at the present time, yet we have this initiative coming forward, which is going to pass, I take it, with the majority—it is one of the priorities of this government according to a document released yesterday. I am concerned that expectations are going to be raised, and then this government will not be able to deliver on it. That is one option. Alternatively, expectations will be raised and too much will be expected from the people who are required to deliver the service, because they do not have the resources.

I would like to have assurances from the government, from the three parliamentary assistants who are here, that they will have the resources to implement this legislation to address the concerns you are raising. Because, in addition to the indirect resources such as residences that this legislation will create, we had a letter or a memo produced last week by Mr Ferguson, something from the public trustee, indicating that just the advocacy services would be from \$6 million to \$48 million, somewhere in that bracket. So I do not know if this government is going to be able to deliver the resources and, second, who it might be leaving high and dry if it goes ahead with this legislation and then cannot deliver on the resources.

I guess I am making a statement more than asking a question. I think you have been working in the field long enough to realize that there have been a lot of good initiatives and good intentions which have not had the resource backup and very frequently it causes more harm than good by doing it in that particular fashion. I just wonder if you feel that you have the assurances that this government has the resources to deliver on this legislation if it were passed this year.

**Ms Hubbert:** I am not close friends with Bob. I have not had any such reassurances. What I do know is that vulnerable adults have been high and dry for too long. You mention that there has been no cost analysis, and I think that it is the beginning. Before decisions like that are made, we need a cost analysis. When we look at that cost analysis, we need to look at what the cost is of warehousing these people inappropriately, and what the cost is of the kinds of medication and health care they require, that they may not require if they were in a better setting, and what some other ways are of providing service that other countries use. So I think it is very difficult to say that the money is not there when the first step has not been done as far as cost analysis.

My concern is that the government of Ontario should be totally embarrassed. And I am not just talking about this government. I am talking about all past governments, where this silent minority of people have had so little

attention and so little concern. Because many of them are totally isolated, have no family members, have no one who speaks up for them, they do not get a lot of the government's attention. I think we really have to look at the moral implications of this whole thing. We also have to look at the cost analysis and other ways of doing it, but I do not think anything should hold up this legislation. I think it is long overdue.

**Mr Chiarelli:** If this legislation proceeds and the resources are not there, what happens? I understand what you are saying, I agree with what you are saying. I am saying that it is easy to offer and it is easy to initiate, but to deliver on it is another question, and we have no assurances that they can deliver on it.

**Ms Hubbert:** We have no assurances of anything. What we do know is that we are looking at the long-term care system because of the way we have been doing business. I am not prepared to look at this one small segment without looking at the whole system, to look at how else business can be done, so services can be extended to these people. It seems that the assumption is made that the services we now provide are cost-effective and absolutely required. I think that all has to be looked at, even if that means that as people from Ontario we have to look at what we consider as a right.

**Mr Poirier:** I am glad I read the details about that fifth recommendation because it says, "Since the involvement of the advocate potentially creates a greater vulnerability" in the sense that what that person may find will evolve from a rights advocacy to a case load. I am kind of shocked to hear that it would take you a year to get the clearance out of the public trustee's office. But from what has been explained to us, I see now that we should not be surprised that the person does not seem to have the resources to be able to do, with all the goodwill that person has.

I am trying to look at this objectively, and what will translate into real life situations. I look at your case loads and how long you have to deal with individuals before the situation is resolved, and then all the monitoring afterwards, to make sure that how you resolved it is always going to be that way a year later on; I mean, you cannot just abandon them. I put it all together and it just reminds me of the former support and custody orders enforcement program in Ottawa, where each case worker had 938 cases of delinquent husbands not wanting to pay child and family support. I mean, I would just love to have a case load like that.

I have a feeling that if it becomes a case-load advocacy, knowing all the needs out there and knowing how long it takes to resolve and monitor to make sure that the resolution is always there a year later—my God, when I look at your presentation, it boggles the mind as to what is required out there to help that incredibly high number of vulnerable people.

I can imagine being a fly on the wall of the Treasurer's office when he says, "Well, if this is what you want, Mr Treasurer, this is how much you will have to give us." If it is up to \$48 million for just the public trustee's office, what is it for the entire program? How do you feel about that? Do you share my fears? What is happening with that deficit?

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**Ms Hubbert:** Certainly I do, but I think there is something we are forgetting. People who are vulnerable can be trained and educated and they can learn. We have to look at whether we are going to maintain their dependence on us for ever or whether we are going to have to focus on their education. York Support Services Network has an advocacy system we use. The first thing we look at is, what does that individual need: do they just need information and then they can advocate on their own behalf, or does the family need information, so that it is done in stages. Our goal is to give people information and education. Initially we may have to advocate for them or with them, but the goal is that down the road their support, their care givers—

**Mr Poirier:** That is right, they do not need you.

**Ms Hubbert:** —will be able to continue that for themselves. The best thing is to see an issue taken and actually see some result from it to encourage them that they do have a voice and that they can make a difference.

**Mrs Cunningham:** The York Support Services Network, in my opinion, the little I know about it, is an advocacy group in itself, the work you do. Am I correct?

**Ms Hubbert:** I would say that.

**Mrs Cunningham:** I think also that you are well known for the kinds of services you provide for the vulnerable adults you serve. You are out there speaking on their behalf all the time. Right now, today, if you had to take each and every one of them, you would probably know how you could serve each and every one of them in a better way. Am I correct?

**Ms Hubbert:** Yes.

**Mrs Cunningham:** I would like to thank you for coming here with that wealth of experience and speaking to what is necessary to accompany this legislation to make anything work. You will not be surprised at all to know that each recommendation requires a lot of resources—dollars. Every one of them I have a dollar sign on, which I am not objecting to, and every one of them requires more communication either through your staff or with families or with the advocates.

There are a couple of concerns I do have. One is as an elected representative. I am from London North, by the way, and have been involved in the same kinds of things you have in the past. Some days I have to sit back and wish there was less bureaucracy and more front-line workers. That is my great concern about this legislation. We have just been through two pieces of legislation, one particularly, Bill 17, which now has our SCOE office in London backed up even more. That is my great fear with this legislation, not that there is not a need. I think it could be more simple. I do not think three ministries have to be involved. I am surprised you did not say that. I would like your opinion on that.

The other one I would really like you to talk a little bit about is something I am very concerned about. Once you get things into legislation, as opposed to providing the services you already know—I can tell by looking at all

three of you that you know what is necessary—instead of doing that we are doing this, in my view. I am really concerned about one part that I thought a little bit about. It is recommendation 7, where you talk about liability, because in my work the best advocates I have ever had have been the family members themselves or neighbours or friends or people who really know the people. Maybe in your work you do not have a lot of that, but certainly where I have been involved it has been somebody who has had some personal responsibility in some way, even to deceased parents or to teachers who have been particularly concerned about young adult students they have watched grow. That has been my experience, so I am really concerned about the personal liability part.

I know I have given you a little bit to think about, but I would like a response to what I have just said in some way.

**Ms Paul:** In terms of the last comment, what I think you are saying, certainly the role of family members and other individuals in advocacy is one that needs to be maintained. We also think there need to be paid advocates. There are lots of people out there who do not have neighbours, who do not have family, who need to have access to somebody who looks after their rights.

**Mrs Cunningham:** I am not arguing about balance.

**Ms Paul:** But we are concerned, and maybe it is just the words we use in terms of personal liability. I am not necessarily saying that you are able to sue somebody if they do not do the work for you, but it states in the legislation that the advocates will not be liable. Our interpretation of that is, how are they held accountable for what they are doing? As Penny said in the presentation, if you do not like what is happening, who do you go to if you cannot find someone who makes your advocate accountable? I do not know if that was what your question was about, but we were thinking very specifically about that group of people and how that will be set up to ensure accountability is there.

**Mrs Cunningham:** No, I am glad you mentioned that your reason for remuneration is that it is at least part of accountability. If you are paying somebody, you can then say they are on the payroll. Through whatever their job description is they are accountable in some way. If that was your point, then that is fine. I respect that.

**Ms Paul:** In terms of the comment about the involvement of the three ministries, yes, it probably makes it more bureaucratic. We also know, just from our little involvement with trying to understand the legislation, that we are dealing with very complex areas. Our response to that would be, I would rather see that all the issues are covered, and if that involves three ministries, maybe that will make for more coordination at the front-line level, because what happens now is that you have got the Ministry of Health and you have got the Ministry of Community and Social Services, and they do not necessarily always see service delivery the same way, and they do not see what their staff do from the same perspective. You get a lot of roadblocks that way and it can be very bureaucratic in trying to get someone's needs met. Maybe by having all three ministries work together on this legislation we will get something

that runs across ministries, that is more coordinated for people so there is less bureaucracy and fewer roadblocks.

**Mrs Cunningham:** It just has not been my experience. As I look around the room, we have three parliamentary assistants here. We have eight lawyers as opposed to two, and all representing the different ministries. I mean, the bureaucracy is here in this room as we discuss this legislation now. Look, I have not got all the answers either, but—

**Ms Paul:** I do not either, but from our perspective this is some of the most far-reaching legislation we have seen in our experience, and hopefully not excess involvement of professionals and ministry people will ensure that it is far-reaching and that we are actually looking at creating something that may be a new experience, that is coordinated and allows people better access.

**Mrs Cunningham:** Would it be fair for me to say that the people you have been working for basically—I think you said this yourself—are people who do not have the family support systems we are hearing about when we hear from groups that represent children, like March of Dimes and what not.

**Ms Paul:** Certainly some of the people we work with do have family support, but we have a large—

**Mrs Cunningham:** Majority of your people—

**Ms Paul:** Yes, a large percentage, particularly the people we work with in the homes for special care population, which we consider an incredibly vulnerable group that most legislation seems to skirt around. I thought I would put a plug in.

**Mrs Cunningham:** I hope we can revisit this down the road and see what happens as a result of it, because if we have not got the resources, we are yet again in Ontario raising expectations, which makes people who are working with these people even more frustrated.

**Ms Carter:** Thank you for your very constructive presentation. I thought if I addressed the question of the adult protective service workers, that might bring into focus some of the other things we were discussing. If they were transferred to the Advocacy Commission, they would presumably lose the case work part of the job they currently do, which would obviously leave a gap. You are saying that should not happen.

But the adult protective service workers who have been here, some of them think they do have a conflict of interest when they are working with an organization that also provides services, whether it is your group or whether it is the Ministry of Community and Social Services or whatever. I am just wondering whether they might in some way come under the Ministry of Citizenship and yet not be part of the Advocacy Commission, and continue to do the job they are presently doing. The point about having the three ministries involved in this whole question is that Citizenship does not have the direct service relationship to the public that Health and Community and Social Services have. Therefore, by placing the advocates under that heading, we are making it much more possible for them to be really at arm's length and quite free from conflict of interest in the kind of work they may have to do. What is your comment on that?

1610

**Ms Paul:** It is more operational, so I will respond to that one. It is a very complex and convoluted issue. Certainly we recognize that in some situations you potentially, in theory, could be in a conflict situation. Our experience, though, has been that it is a tradeoff; you pick up some things and you lose others. We have also been at an advantage many times working very closely with both ministries. We get funding from the Ministry of Community and Social Services and the Ministry of Health. We know those systems well. We have contacts within those systems, and many times we have made those systems work for us. By knowing that system well and having a knowledge of it, we have been able to meet the needs, get a lot of funding for people's needs going through that system.

Part of the difficulty is, and it is an issue of one's experience, a number of the adult protective service workers have been in agencies that have not known what case management is; they are sort of add-ons. Our staff has been fortunate because we are set up to do that. We have a very different perspective on how well you can work within the existing system. If you have a strong system and a strong board, it will basically say, "We receive funding from the ministry, but that does not mean we can't advocate to them when we have a client's needs to deal with." We have taken that stand and we have been very successful with it.

Part of our concern with the Adult Protective Service Association of Ontario is this feeling that everything is going to be resolved if you move over to Citizenship. Our thought was, let's look at what the issues are within the ministry first of all and see if we can resolve some of those operational and conflict issues before you take a whole program and move it over. We just do not think that first step has been done.

**Ms Carter:** So your big concern there is really to keep their function as it is and not dismember it?

**Ms Paul:** Yes, that would be our preference. Certainly our staff do social advocacy as a matter of course. We also see a point where we could well be in conflict and we would pull in an advocate from the commission to become involved with that particular situation.

**Ms Carter:** I see.

**Ms Paul:** But on a day-to-day basis, a lot of what we do and a lot of what our adult workers do is social advocacy.

**Ms Carter:** I just have one other point. Of course, the advocates envisioned under Bill 74 have a second function, which is systemic advocacy. In other words, if they find from the clients, the people they are dealing with, that there is some problem out there that is affecting all those people or many of those people, they are empowered to do what they can to correct those problems. That is relevant to what came up earlier in this discussion as to whether this whole thing is going to cost a lot of money, because if we find that problems in society are being dealt with and rectified, then I think we could expect that would not only lead to more happiness, less suffering, but also to less expenditure of public funds. Do you agree with that?

**Ms Hubbert:** Yes. I would just like to make a comment about the APSW and the conflict of interest. If you

want to see conflict of interest, look at an agency like YSSN, which is being funded by the Ministry of Health or the Ministry of Community and Social Services: We often run into situations where our clients are not getting the service and we have to advocate and assist them. I do not think it is a matter of trying to protect people by keeping them out of any situation where there may be conflict of interest; it is a matter of training and education. We are professionals; we recognize when there is a conflict of interest. When that situation occurs, you handle it and you bring someone else in.

Around systemic advocacy and community development of services, this is something else that YSSN does. We get around it by educating and encouraging the consumers to take a lead role in assisting with that kind of initiative. But it gets back to education and training. The whole issue of cost analysis for the government—not just for this one program but for the government—and for education and training, whether you are talking about health, community services, whatever, it is key. We are constantly going to be hand-holding people unless we give the necessary importance to the education and information to people.

**Ms Paul:** Could I just respond quickly to the comment?

**The Chair:** Quickly.

**Ms Paul:** One of the concerns we have with the split with the workers is that they are going to be expected to be a rights adviser, a case advocate and a systemic advocate. Our concern is, given the clear direction in terms of a time line for being involved as a rights adviser, we may be wrong but we think there is going to be a lot of need for that. The question will be, will the advocates be able to do the systemic? We are worried that it is going to get sliced off because there is going to be so much demand for the here and now: "I have this issue. It has to be resolved in two weeks or three weeks," whatever. They are going to have all these issues, but the question is not to lose that systemic part of it, because we think that is essential.

**Ms Akande:** This advocacy system is quite an interesting design. It is really a design that is not supposed to be confrontational; it is supposed to be supportive and protective. It is interesting that you and Mr Woronko before you saw that as its goal.

I was interested in page 4 of your presentation, the bottom paragraph. One of the things you have included in that is that of the people you serve, 70% required advocacy services. I was wondering whether in fact the service coordination agencies that will come out of long-term care and the resultant coordination of services through that system would not in fact take some of that load from you.

I am familiar that currently the APSW workers do a lot of service coordination for the people they serve. It does in fact take a great deal of time also because the agencies and the services are not set up in a neat little package of districts and so you have to go and shop and find and sometimes bang on doors.

When the service coordination agencies move into existence, will that not lift some of that from the work you do?

**Ms Hubbert:** Right. It will depend on whether the focus of the long-term care is expanded to include other

than seniors and people with disabilities, and how soon that happens. Also, we have some concerns around the SCAs because if we are looking at education and giving people training and giving them the encouragement they need to develop themselves, you cannot do this in a very quick manner. It takes time and it takes energy and you have to go at that person's pace. I just do not know whether the SCA—who knows how it is eventually going to look, given the other responsibilities they are going to have, whether they are going to be able to provide that?

**Ms Akande:** Currently there are services that are designed to educate the very populations you serve, where that population was included in long-term care. Those services were part of the network the service coordination agency would refer to. Would that not serve part of the need you have just described?

**Ms Hubbert:** It would. My concern is around when you say "educate," because all of us learn through our own life experiences. A lot of the vulnerable adults and children have not had that opportunity because they have not been able to take those kinds of risks. So when I say "education" I am not referring just to formal education. I am referring to the education you get when you have someone who is supporting you and assists you through those life experiences that you learn from.

**Ms Akande:** One last, if I may.

**The Chair:** If it is very short. Mr Malkowski would like a brief question also, and we are over time.

**Ms Akande:** I am very brief, and you will recall that we have not had much time. I will not pull a tantrum. Thank you.

I want to say very quickly that certainly the educational resources I refer to in relation to the populations you serve would of course use appropriate life experiences as part of their teaching technique. They generally do.

One of the other services you have referred to is making the ministry work for you. I know exactly what you mean by that, and you are indeed effective. One of the things I was responding to is that there too is a job that might well be affected by the service coordination agencies. Am I not correct?

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**Ms Paul:** The actual advocating with the ministry to get funds?

**Ms Akande:** The actual knowing where the services are and which door to ring, which buttons to push to get those kinds of things. Would that the LTC was extended to include that population, that could in fact be.

**Ms Paul:** Certainly it would make sense that they would have that knowledge base and those contacts. I guess our concern is that at this point we have heard very clearly they are targeting long-term care to two populations, and those two populations do not include the populations we work with, at this point. But we hope in the future that resource will be available to people.

**Ms Akande:** One of the questions in—

**The Chair:** Ms Akande. One brief question and response from Mr Malkowski.

**Mr Malkowski:** I wanted to ask Trudy to clarify the term "personal liability," which was raised.

**Ms Spinks:** The question addressed the presenter's concern regarding section 9, which says that an advocate cannot be sued for actions undertaken within the scope of his or her duties and in good faith. This section also goes on to impose liability on the crown for those actions with respect to advocates who work for the commission. It is not intended that a vulnerable person or someone else who suffered damages does not have recourse; it is simply that advocates will not be totally constrained in what they do by fear of losing their personal assets and so forth, consistent with police officers and human rights officers.

**The Chair:** Thank you for that clarification, Mr Malkowski. Ms Hirstwood, Ms Hubbert, Ms Paul, on behalf of this committee I would like to thank you very much for coming and giving your presentation.

**Ms Hubbert:** Thank you very much.

ROBERT WALSH

**The Chair:** I would like to call forward our next presenter, Mr Bob Walsh. Good afternoon. I would like to remind you that you have half an hour for your presentation. We would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the committee members. As soon as you are comfortable, please identify yourself for the record and then proceed.

**Mr Walsh:** My name is Robert Walsh. I am a consumer-survivor. I have a thought disorder; I am a schizophrenic. I really appreciate the opportunity to address this gathering and I would like to thank you for the opportunity to share with you concerns in regard to the various acts you have gathered here to confer on, evaluate and assess. It is my prayer that God will give you great insight in these issues because there are many concerns here. I trust that what is done here today will mould and shape our future, for better or worse, for many years to come.

I understand that my opinion may not be a collective voice for the public at large, but I have received overwhelming support for an amendment I petition you to make within the newly proposed laws. Many recipients of mental health services with whom I have had cause to converse have indicated their support for this amendment that we feel we need. This amendment could be the difference between someone getting help and someone falling through the cracks of the system. I am sure by now that you are very familiar with many of the statistics of mental health issues, so I will be very brief here.

Schizophrenia universally is accepted to be manifest in about 1% of the population. It is a very democratic illness, as it is present in every group more or less equally, but the stigma of being mentally ill prevents many from becoming familiar with the facts.

The population of Canada, I have been told, is some 23 million people. That 1% factor then calculates to include 230,000 Canadians; that is nearly a quarter million people. Another factor of real interest is that 10% of all people suffering from schizophrenia will commit suicide; in other

words, 23,000 Canadians who are schizophrenic will kill themselves. The facts I am quoting have been confirmed by the Schizophrenia Society of Canada.

Friends, schizophrenia is a real problem within my family. I have had one uncle who killed himself. I am also haunted by the memory of an older brother who took that way out. I also have a sister who has tried this and I have attempted to do this many times myself. But it was never really evident that any one of us would do this. My uncle, when he killed himself, was in a sanitarium. He handed his gloves to his sister, dove out the window and killed himself. I was hospitalized myself in intensive care for a number of days due to a prescription overdose. On another occasion, I was stopped from certain death as I sat in a vacant lot with my car engine running and the exhaust fed back into the car by a hose. The gas gauge was broken and it is only providence really that I did not succeed in my plan. My dear wife is only recently aware of this attempt. Again, I am a sufferer of the disabling thought disorder, schizophrenia, and I am very grateful to have been helped by the mental health community at large. Today I can stand before you because of the many people who have assisted me and the fact that I did not reject their help. I have been hospitalized eight times in the last six years.

When I am functioning well, I am for the most part quite able to make rational decisions about many of the issues life presents me with. I try to avoid stress wherever and however I am able, and in anticipation of stressful events, I, with my doctor's approval, increase the medication I need to stay well. In fact, in preparation for this presentation I am making here today, I have increased my medication by 50% since February 7.

The common denominator throughout each hospitalization is that I am very paranoid. When I initially lose touch with reality, I believe my care givers will and do try to kill me. But when I recover a bit, I realize that most of my paranoid thinking is due to my degenerated thinking. I believe it is only a matter of time, however, before I do reject help.

Each time I am hospitalized it becomes more difficult for me to submit myself to others' care, because they have a different perspective than I do. In order to get the help, I have to rely on their perspective and close my eyes to mine. If I refuse help when I am ill—I can tell you that now, while I am well—this is simply not an option, but with a change in perception comes a change in choices and options. It is most irresponsible to overlook this factor of mental health dynamics.

I am asking you to give me a tool that will give me the right when I am well to contract with my care givers I trust when I am well; to administer intervention that I approve when I am well, allowing myself to reject my pending rejection that will inevitably be expressed when my judgement becomes impaired.

Those who would not make such a contract will lose nothing by way of their rights to reject any treatment that can be expressed whether due to poor judgement, fear or irrational thinking.

I believe I have the right to make such a request. Additionally, I believe it is a breach of the Human Rights Code

not to allow me this option. The Human Rights Code, 1981, states: "And whereas it is a public policy in Ontario to recognize the dignity and worth of every person and to provide for equal rights and opportunities without discrimination that is contrary to law." I want that equal right and I feel that is my right. This right will not be there unless you allow me to be empowered to make such a contract because I believe inevitably, sooner or later, I will refuse treatment.

The Canadian Human Rights Act states, "Every individual should have an equal opportunity with other individuals to make for himself or herself the life that he or she is able and wishes to have, consistent with his or her duties and obligations as a member of society granted." I would like to highlight the words "duties" and "obligations." I feel I have a duty to myself to look after myself, considering all the circumstances of my present situation.

I have for your consideration a number of signatures to show support for an amendment I propose here today. Almost every person I have approached personally signed to show their support. Further, many of these people are schizophrenic. In fact, I really did not come across anyone who did not show support for such an amendment.

What does such an amendment mean to us? When well, people can contract in advance, rejecting their rejection of treatment in advance. They will get better and that means more people staying well, fewer people killing themselves; more people staying productive and fewer people living on the streets.

1630

Between 50% and 60% of the people on the streets, I am told, are schizophrenic, and I do not doubt you have heard this already. Perhaps you will hear it again. There can even be a time-limiting instruction in the contract. With more people staying productive, the annual national bill of \$2.5 billion due to schizophrenia alone could be turned around. The self-sabotaging barrier of treatment will be broken, and we will keep our minds and hearts and lives.

Such an amendment, I feel, is not only rational, but both realistic and socially responsible. Dear and honourable friends, what you do for me here you will also do for that 1% of your family and their future generations. Not to understand this issue and not to make a provision for this dynamic schizophrenia, I feel, is insanity itself. By making such an amendment you are not removing the rights of others who would oppose this request.

Thank you very much for your time. I will try to answer any questions you might have for me.

**The Chair:** Thank you very much. Questions and comments, Mr Chiarelli?

**Mr Chiarelli:** I have a comment and also a question. First of all, from my experience with that particular thought disorder, there is nothing factually incorrect in what you have said today. I will tell you, as a member of this committee, the government will introduce an amendment to accommodate you and people with that particular illness. If they do not, I will, and I will filibuster this legislation as long as I possibly can until an amendment of this type is introduced.

However, I also have a question. You have described a solution, or a possible solution, to help prevent people from killing themselves, which is very common with people with schizophrenia, but do you have any suggestions for this committee about what changes can we make in the legislation for the first-time occurrences?

You are obviously addressing a situation where a person has already had an episode or some type of involvement with the illness, and therefore you want some future prevention. Do you have any suggestion in this legislation for a first-time occurrence, if there is a strong suspicion or a strong opinion on the part of a medical practitioner that someone in an emergency situation is suffering a schizophrenic episode, that they should have the authority to do something under those circumstances?

**Mr Walsh:** Thank you very much for your comments to support the idea of having a law made to allow some of this that I have communicated. I am sure many people, if this happens, will owe their lives directly to that kind of intervention.

As far as people are concerned who are becoming ill for the first time, I would first of all like to point out that many times, when people first become ill, they are probably more ill than they will ever be again; they might believe that the people here to help them could be Satan himself. Even if you did have an advocate to work on your behalf, the first thing you have to do is accept to have someone do that.

I propose education throughout the system, in high schools, grade schools and things like this where advertisement could be done. Just as you have a will to distribute your property, you should also have a contract that you can make to help protect yourself should that ever happen. It is quite a reasonable thing to deal with your death, but how much more real and reasonable is it to deal with your life?

Traditionally, very few people know what schizophrenia is, and they will not know and they probably will not know about anything that might be able to be placed unless they are educated to do that. What I propose is something in line with the Graham report that was recently made affecting our community, that education should be supported and funded. I think education is really the answer in a lot of these issues with schizophrenia, and I think it might be very difficult to do anything without education.

**Mrs Cunningham:** Just a comment. First of all, I sincerely thank you for coming before us today and for taking the time to bring not only your points of view but those, obviously, of many of your friends. I am certain that the government in fact will consider this kind of amendment to allow you, certainly, to put your wishes on paper with regard to your future care. I do not think there is anybody in this room who would not consider that a reasonable amendment, and so we look forward to that happening. Perhaps one of the government members, when it is his turn, could respond to what I have just said. If there is a problem with it, I think both you and I would like to know now what that would be. Thank you very much.

**Mr Winner:** I too would like to thank you for your presentation. I need to know a couple of things from you. One is, let's say you wrote down that no matter what

happened, if you needed the treatment, no matter whether you objected to it at the time, that treatment would still be given to you. How long would that last? Would it last a lifetime? Would it last for six months, 12 months, two years?

**Mr Walsh:** That is a very good question, and I think that like making the contract when you buy a house, it is, in effect, that you pay the mortgage until the house is paid for. As far as making a will is concerned, that is basically okay until you change it. I think you could look at the possibility, if it had to be agreed, that everyone would say, "Let's limit the time factor of this."

We can be educated to know how frequently we have to recontract. This is something that could be changed to anything from a very short, one-year time, let's say, to a much longer period of time. I think we are looking at something that people can change as they feel they are able to. The thing to look at, however, if we are to make a change, is that we have to be fairly rational to make that change, and I think if we are rational enough to make that change, then we should be able to make that change in any way we wish to make it.

**Mr Winninger:** I see. A second question: As you know, treatment modalities change, new medicines are created and utilized. Let's say, for example, you signed such a document. I take it it would be in writing, you would state your intention in writing that you would receive treatment, no matter what.

**Mr Walsh:** Yes.

**Mr Winninger:** Let's say a new drug came along, let's say clozapine, and it is found to be a kind of miracle drug in most cases. But in 5% of the cases, as one of our earlier presenters indicated, it could possibly have side-effects, it could possibly be life-threatening. How would you deal with that in your original document, where you waive your right to refuse treatment now and for ever?

**Mr Walsh:** That is a very good observation. The fact is, though, if you recall, I have the risk of developing tardive dyskinesia on the medication I take presently, and I choose to take this medication to allow me to continue to live a somewhat normalized life. Without the medication, I am quite irrational. I could even believe that I am God, and if I am God, then who should I subject myself to? That is the danger for me, but there are risks of side-effects and things like that right now. I make an educated choice to take the neuroleptic medication that I take.

As far as new drugs are concerned, we are talking about a personal and an individual contract. If I wish to try a new drug that might be controversial, then let me do so if it is at my own request. If it is legal to be available to me, then let me do so as I feel I can do that. While I am rational, let me make that contract. If, however, I feel that would be more of a risk than I would like to take, then while my judgement is not impaired, let me also stipulate that I will not take that drug.

Presently, I have a number of drugs that I will not take because of bad experiences with drugs, and that really only comes through time and knowing how things are. I would not take some drugs, for example, that I have heard some

negative things about until I could see for myself how effective they could be.

**Mr Winninger:** So you are not signing a waiver here; there are some drugs that you would not want to be treated with in any case.

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**Mr Walsh:** Exactly. I think what you have to make sure is that this contract should touch base on those things that any individual might like to deal with. Just as in a will, where you touch base on all your assets, you also have to look at the whole picture when you make such an agreement.

**Mr Malkowski:** Thank you for your very impressive presentation today. I think it is a very important education that you are providing us. As far as keeping stable by use of your medication is concerned, we have heard of some situations from psychiatric survivors, and they have talked about some of the misdiagnosis and mislabelling that happens with people who are diagnosed schizophrenic. I think the advocate is there to help prevent that kind of misdiagnosis happening. Would you agree that making sure that those people have the right to refuse treatment if they have been diagnosed as schizophrenic would be one of the roles of an advocate in those situations?

**Mr Walsh:** Again, you have to be looking at the fact that when a person makes this kind of agreement, he is fairly rational, and with proper counselling he will be able to look at the whole picture. I would not say, "Stop buying canned food," because every now and then you buy a can of food that may be tainted, because you have to eat. And I have to live: In order for me to maintain the quality of my life, it is very important that I be free to choose the best things that are available for me as I perceive them while my judgement is not impaired.

**Mr Malkowski:** I have one more point I would like to clarify, then, related to the psychiatric survivors who have presented to us previously. Some of their experiences have been that they have been misdiagnosed as schizophrenic. Would they have the right to refuse treatment? Would you be supportive of that, of the Advocacy Act, and agree that if there are some people who are misdiagnosed as schizophrenic, they should then be able to refuse treatment?

**Mr Walsh:** To reply to that, I would like to look back at the Human Rights Code. I think if their decisions are well made and made in reality, or are made before they come to that problem, or even made in error, we also have to recognize everybody's rights.

My perspective of myself is different and, even in myself, the awareness of what is wrong with me is a long kind of journey. If I just look at the system the way it is now, I have to ask, what is happening with these people now? My point is that by allowing me to make a contract like I am describing, I am not taking away anyone's rights, and I feel that is the way it should be, perhaps. There have been some abuses; I understand and I am aware of that, and I am not kicking about that, because I think it is very commendable to try to deal with these things. But I am talking about myself personally, and I feel that other people share my perspective, and that is really why I am here today.

**Ms Akande:** One of the things that most interests me around the presentation—and I must admit that I am very interested in what you are requesting—is that just as you would recommend or sign a paper or designate someone when you were well to take care of you when not well, what if it was required if you decided at some point in the future to change that designation? Would it not require—I really do not know, and I do not know even if you know—that someone, a doctor, be assigned to determine whether at the time you wanted to change the designation you were well enough to do so?

**Mr Walsh:** Yes. I think because of that, one thing you have to look at is that just as a will can be changed when the circumstances change, it is important that this be changed as well. I think the question of having someone who can certify that you are reasonably well to make that change—you should be able to make that change at any time. However, when you are acutely ill, my concern is that you not simply walk away from treatment because of your perspective, which is distorted while you are ill. I think it would be inappropriate for me to make a change while my perspective has changed, yet if I am still rational and reasonable and I have come to realize a new dynamic within my problem, even new medication, then yes, it is very necessary that this can be changed.

I think that whatever you talk about, when you talk about the Consent to Treatment Act or any of these other advocacy acts and what not, someone really has to make a judgement call in some way to empower someone. That is not a difficult thing to do when you are talking about someone who physically cannot speak and cannot communicate. Someone has to be there to help that individual. But when we are well and rational, we should have the right to control that area by saying: “If I do reject help when I am ill or when my judgement is impaired, then treat me. However, while my judgement is not impaired and I wish to make a change, I need the means to do that as well.” I would not suggest that someone live the rest of his or her life based on something they signed one day, and live with it for 80 years.

**Ms Akande:** No. The point I was making, though, is that there would have to be some judgement made about your ability at the time you wanted to change the designation.

**Mr Walsh:** I would agree with that, absolutely.

**Mr Wessenger:** I just have a short question. Would you support the concept that when you entered into such a contract and designated your health care, an advocate should visit you to advise you of your rights?

**Mr Walsh:** I have no problem with learning about my rights and making sure they are not infringed, but I have to be very specific to answer something like that. If when the advocate comes I am telling him, “I want out of here,” and I know my own plan is up to no good, that I am delusional, and that advocate can look at my contract and yet still allow me to be released without treatment, then I have defeated my own goal.

**Mr Wessenger:** I think my question really relates to the time you are entering into your contract to designate. It has been suggested that when a person enters into a contract, he receive advice at the time, be attended by an advocate.

**Mr Walsh:** Exactly. It is very effective and very important that that is also there, because the more people who are there to give information, the more educated a choice can be made. We could definitely benefit from being able to talk to someone who is trained to be an advocate, who is aware of certain conditions and certain problems, when we make a contract. I would like to say, though, that it should not be mandatory. It should be a personal choice, perhaps. But I would not turn my back on any information to make any kind of logical or rational decision about my health and staying well.

**Mrs Cunningham:** This is really a subsequent question, probably, to all that were asked, but I particularly thought of it when David Winninger was asking his question. At some time in your life, you probably have somebody whom you would really trust to help you make decisions. Would you consider that person's name being part of this contract or agreement? Do you think it would be important to put a person's name in this contract as somebody who, at least as far as you are concerned, would always be there even to listen to an advocate or a medical adviser or somebody? Is that something you would want to see happen?

**Mr Walsh:** I think that should be an option that is available, and an individual can make a personal decision about that. I do not think it should necessarily be a standard kind of thing. I think what is really important is to allow the individual to make the contract. Some people will have someone whom they can trust to understand what they meant by that contract and to ensure that the right of that contract is enforced. In that regard, I think that could be very positive. But I do not know enough about that to really make an effective statement about it.

I trust my wife, I trust my family doctor, and I have always involved them any time I have been ill. But like I say, it becomes more difficult as I become ill to submit myself to treatment, and that is really why I would say have the contract. Those people who are there and whom I trust will be able to do very little if I make a bad decision and refuse treatment. Even those people who are named may not be able to do anything unless there is a contract where they can say: “No, Dr Smith, my husband really wanted to be treated. He agreed to take injection, long-term medication, and he did not agree to take shock treatments. He agreed to take any drug that was working in the system that had been known for greater than three years, but not to take anything that was a brand-new thing.” Those are all kind of personal choices.

**Mrs Cunningham:** So it is the same response you gave Mr Wessenger with regard to his question. The reason I ask is that there have been instances where family members have been—I have to be careful in my choice of words, but people in agencies have not thought they were working in the best interests, and therefore they go to a different advocate. This is a reality of life some days. Who is to judge? When you are feeling well enough to make decisions with regard to people you trust, I just think it would be important that you say so. But I appreciate your response that it is not something that has to be mandated but is something that should be considered by each individual.

I really admire you for coming here today. You have been very helpful.

**Mr Walsh:** Thank you very much.

**The Chair:** Mr Walsh, on behalf of the committee I would like to thank you for taking the time out to come and give us your presentation today.

**Mr Walsh:** I would like to thank you for allowing me to do so.

**The Chair:** Seeing no further business before the committee today, we adjourn until 10 am tomorrow morning.

The committee adjourned at 1652.

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Spinks, Trudy, Ministry of Citizenship

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**Staff / Personnel:** Swift, Susan, Research Officer, Legislative Research Service





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First Intersession, 35th Parliament

## Assemblée législative de l'Ontario

Première intersession, 35<sup>e</sup> législature

# Official Report of Debates (Hansard)

Thursday 20 February 1992

# Journal des débats (Hansard)

Le jeudi 20 février 1992

## Standing committee on administration of justice

Advocacy Act, 1991,  
and companion legislation

## Comité permanent de l'administration de la justice

Loi de 1991 sur l'intervention  
et les projets de loi  
qui l'accompagnent

Chair: Mike Cooper  
Clerk: Lisa Freedman

Président : Mike Cooper  
Greffière : Lisa Freedman

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# LEGISLATIVE ASSEMBLY OF ONTARIO

## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

Thursday 20 February 1992

The committee met at 1008 in committee room 1.

ADVOCACY ACT, 1991,  
AND COMPANION LEGISLATION  
LOI DE 1991 SUR L'INTERVENTION  
ET LES PROJETS DE LOI QUI L'ACCOMPAGNENT

Resuming consideration of Bill 7, An Act to amend the Powers of Attorney Act; Bill 8, An Act respecting Natural Death; Bill 74, An Act respecting the Provision of Advocacy Services to Vulnerable Persons / Projet de loi 74, Loi concernant la prestation de services d'intervenants en faveur des personnes vulnérables; Bill 108, An Act to provide for the making of Decisions on behalf of Adults concerning the Management of their Property and concerning their Personal Care / Projet de loi 108, Loi prévoyant la prise de décisions au nom d'adultes en ce qui concerne la gestion de leurs biens et le soin de leur personne; Bill 109, An Act respecting Consent to Treatment / Projet de loi 109, Loi concernant le consentement au traitement; and Bill 110, An Act to amend certain Statutes of Ontario consequent upon the enactment of the Consent to Treatment Act, 1991 and the Substitute Decisions Act, 1991 / Projet de loi 110, Loi modifiant certaines lois de l'Ontario par suite de l'adoption de la Loi de 1991 sur le consentement au traitement et de la Loi de 1991 sur la prise de décisions au nom d'autrui.

**The Chair:** I call this meeting of the standing committee on administration of justice to order. Just as a reminder to those still using the pink schedule, our 9:30 has now moved into the 11:30 slot.

### PROVIDENCE CENTRE

**The Chair:** I would like to call forward our first presenters now, from Providence Centre. Good morning. I would like to remind you that you have a half-hour for your presentation. The committee would appreciate it if you would hold your remarks to about 15 minutes to allow time for questions and comments. As soon as you are comfortable, please identify yourself for the record and then proceed.

**Ms Smyth:** My name is Margaret Smyth. I am a member of the ethics committee of Providence Centre as a representative of the residents' council. This is a submission to provincial committee on the administration of justice regarding the Advocacy Act, Bill 74; the Substitute Decisions Act, Bill 108; the Consent to Treatment Act, Bill 109, and the Consent and Capacity Statute Law Amendment Act, Bill 110. Dr Ferguson and I have had several discussions over the last couple of weeks regarding these bills and what I am presenting is my own version.

I have several impressions regarding these acts. My first impression was that the bills were hard to follow,

required a lot of backtracking and re-reading and were often repetitive. I ended up with more questions than answers.

An example of repetition lies in Bill 74, sections 1 and 7. Clauses 1(c), (d), (e) and (f), which purport to be the purposes of this act, seem more appropriately to belong to section 7, which merely states, "The commission shall,"

As a "vulnerable person," as in section 2, by virtue of lacking physical ability to act on my own wishes, I see some merit in one of the alleged purposes of the act spelled out in subclause 1(b)(ii) and clause 7(1)(c), but it does not seem to be further elaborated upon, except for clause 36(a), which allows the commission to make regulations regarding advocacy for change at the political, legal, social, economic and institutional levels. This is a lobbying function.

Subsection 6(2): It hardly seems possible to divide the 12 members of the commission among all—how many?—regions of the province and be representative of all the categories named.

Clause 7(1)(a): Other than by a public relations campaign, I do not know how the commission can "promote respect for," naming individuals. I would find this more credible if the words "promote" and "for" were deleted, leaving the word "respect."

Subsection 3(2) and other references: I have not found a definition for "community development" or "community development strategies," clause 7(1)(e), and I am quite in the dark. I do not know what these are.

Section 14 re appointments to appointments advisory committee, recommendations to be made by relevant category: I personally belong to four categories. Incidentally I do not see that age 65 alone should be a qualifying factor, paragraph 15(1)3.

Bill 108:

I have not studied this bill sufficiently to grasp the full import, but I do find the terminology confusing. The number of possible people involved is daunting. I will list some: power of attorney for property, statutory or court-appointed guardian of property, public guardian and trustee as guardian of property temporarily, guardians of property, guardian under continuing power of attorney, power of attorney for personal care, court-appointed guardian of the person, court-ordered full guardianship, court-ordered partial guardianship, advocate, representative, agent and counsel. The proper place of all these people in administering the act is not clear.

I have some observations.

Clause 3(1)(b): If the capacity of a person is in issue, how can that person have capacity to retain and instruct counsel?

Paragraph 10(2)4 limits who can act as a witness. In a chronic care facility, the possibility of finding two

witnesses who are willing to make a written statement regarding capability of a person, subsection 10(3), is in doubt.

Subsection 16(5) seems to assume that there is a pool of advocates waiting to be called. Under clause 16(5)(b) I am not sure if there is a follow-up if statutory guardianship is refused. The same applies under subsection 20(5) when guardianship is terminated.

Subsection 17(1): It took several readings for me to understand that the attorney may apply to replace the public guardian and trustee. The wording is misleading and it could be taken that the attorney is applying to be replaced by the public guardian and trustee.

Subsections 22(1) and (2): There are a court-appointed guardian of property and a statutory guardian. Which takes precedence?

Subsection 27(5): "An advocate shall meet with the person before the hearing." This is the first mention of a hearing.

Bill 109:

Subsection 6(2): I find it difficult to envisage the situation where a person is capable with respect to some treatment and incapable with respect to others. The concept smacks of authoritarianism.

Subsection 10(3): It does not put much responsibility on the advocate, who could brush off any failure to explain by saying, "I did my best."

Section 20: An incapable person can apply to the Consent and Capacity Review Board to appoint a representative to give or refuse consent to treatment. In the outside world, I would call this person an advocate, but that word has been pre-empted and given a very narrow definition by the Advocacy Commission.

I cannot help feeling that the intent of the bill is to deny vulnerable persons the right to refuse treatment. The health practitioner has an inordinate amount of power with respect to the determination of capacity.

In summary, I can see a need for regulations concerning Bills 108 and 109 but fail to see what Bill 74 accomplishes except to set up a bureaucracy. The advocate has no power since the service can be refused and the only function is to contact persons who have been declared incapable and tell them their rights, which they have already been told by the health practitioner, yet they are given other extraordinary rights.

It is not always clear to me how the bills tie together. Is it always a requirement for an assessor or health practitioner to call an advocate, regardless of involvement of attorneys or guardians, when incapacity is determined? What a lot of red tape.

Overall, the bills seem to subordinate the rights of individuals and their support groups, including families, relative to a bureaucratic process that can only hope to benefit a few vulnerable persons who are truly alone. In the process, it seems to be quite intrusive in the rights it gives to advocates, with rights of entry and rights to confidential documents. I am left with a question, does the advocate do anything the health practitioner has not already done? And whose purpose is served, the vulnerable person or the advocate? This subordination of families does not dovetail

well with the long-term care proposals being put forward by your government, where families will be expected to provide more care in the future.

1020

**Mr Phillips:** I appreciate your presentation. Just in terms of how this might actually impact on you, have you and your group discussed what the practical implications of these three bills might be on yourself and the group you are representing?

**Ms Smyth:** The main thing, it seems to me, is that advocates are given a position that is totally unnecessary, in most cases to the detriment of families.

**Mr Phillips:** Have you seen, on the other hand, examples where an individual would have benefited had these bills been passed? Have you seen cases where this could, on hindsight, have been a good thing, to have these bills in place?

**Ms Smyth:** Personally I have not. I am sure there must be some vulnerable people in the community who could benefit.

**Dr Ferguson:** Perhaps I can answer that a little more, just because of my experience. There are sections in the act that I think would benefit those of us who work in the community in so far as I can see some benefit for people we see whom we might consider vulnerable and there is no avenue for providing them with any assistance.

The difficulty with the current legislation is that the only avenue we can use sometimes to get somebody help is under the Mental Health Act, which I think is the wrong act to have to resort to all the time when we are often-times talking about somebody who has dementia and a failure to thrive, who is becoming progressively more ill physically and there is very little you can do except under the provisions of the Mental Health Act.

Under Bill 108, say where you can make application for guardianship, there is an opportunity to provide some help by another avenue, under other legislation, that does not have the stigma that is attached to the Mental Health Act, but also it allows other people to participate in the decision-making process. I think that is a benefit.

One of the difficulties in the act—Marg and I have talked about this—and one thing I worry about is that after 10 years in the community I will be called upon as an expert to assist other health care providers in their decision-making and to evaluate somebody. I do not know what the impact of this act will be under the terms of Bill 108, because right now I tend to be fairly libertarian in my viewpoint and I do not admit people who want to stay at home, even when they may be at some risk. As an individual practitioner I will probably allow a greater degree of risk than some other people.

Under the new legislation, I can get bypassed entirely. I might not now be called upon to see a vulnerable person in the community because health care providers, other people and other disciplines and families and friends do not like me because I do not admit people to hospital, because I do not override their wish to stay at home. I can get bypassed totally by this legislation. I would argue that a peripheral and remote guardian will assume a social standard of accept-

able behaviour and acceptable living conditions that are probably higher than the standard I will accept, or that I can live with and that the person, I think, can live with.

My concern is that the consequence of Bill 108 may be that you end up institutionalizing more people or hospitalizing more people because there may not be the level of expertise required to do evaluations, and a kind of acceptable social value may be the standard that becomes used. None of my patients—I guess that is an exaggeration. Let's take the more severely demented patients I see in the community. They do not fit the standard of personal care that is defined in the terms of Bill 108. They are still out there, but they do not fit the standard. They would not qualify to have an understanding about any of those issues regarding dress, living arrangements etc. They do not fit and I do not know what that would mean. Once they got declared incapable, what would that mean to them?

It really all depends, I think, on the wisdom and discretion of people acting under the terms of the act. If good people are out there attempting to do good things and have great respect for other people, it will not be a problem. If you get people whose agenda is to rescue other people, then I think there will be a tremendous intrusion on privacy and potentially we might actually be harming people.

**Mr Winner:** Thank you for your presentation. There are a few points you make in regard to Bill 108 that I think might be addressed. First of all, you questioned, if the capacity of a person in an issue, how can that person have capacity to retain and instruct counsel. There is always a presumption that a person has the capacity to retain and instruct counsel, even in the case of the criminally insane or people who are certified. It is just a right that people are entitled to no matter what their capacity is. To the extent that a lawyer can obtain instructions from that individual, then that lawyer can represent that individual.

Another point you raised was in regard to whether there is follow-up if statutory guardianship is refused or terminated. This is under guardianship of property in the bill. I would just note that section 19 provides that if a statutory guardian of property ceases to act as such, for any reason, the public guardian and trustee may act as the incapable person's statutory guardian until a new application to the public guardian and trustee is made, or an application to the court under section 22. I think section 19 addresses your concerns there.

I am not so sure what your concern was about section 22. It says: "There are a court-appointed guardian of property and a statutory guardian. Which takes precedence? It is possible, as you observed, for someone to have one guardian to administer property and another guardian of the person. That is certainly open, because in some cases a guardian may have more expertise when it comes to dealing with property and in other cases a guardian may be better able to deal with personal needs. So it may be appropriate in some cases that the guardians be different for property and personal care.

**Ms Smyth:** The question arose, really, because of my lack of understanding of all these different terminologies. I just could not sort it out.

**Mr Winner:** I agree that the language is complex. Because these are complex issues, the language sometimes needs to be complex as well to deal with all the contingencies.

**Ms Carter:** I am really sorry that you view the Advocacy Act in the way you do. First of all, to answer some of your separate little points, given the size limit of the commission, I think our provisions for it to represent the kind of people it is going to be serving are very good. It is not going to be a powerful bureaucracy; it is going to be at arm's length from government. It is under the Ministry of Citizenship, which is not a ministry that delivers services directly to the community, and it will even be independent within that.

The over-65s have told us they think they should have more rather than less representation, because they have a lot to offer, but that is a matter of opinion. I do not think we could really define all the community programs that might come under this. I do not see how we could do that.

But as I say, I really feel that you have misunderstood it completely. First of all, it is not for people who are totally incapable; it is for the vulnerable, who may be vulnerable because of the situation in which they find themselves. It is only to listen to their wishes. That is the sole function of the advocate, to meet with the person, to find out what he wants and to try and carry out those wishes and if he find that a lot of people are having the same class of problems, to try and change things in the community that will tend to overcome those problems.

Where family and friends are on the person's side, as is very often the case, there is no problem, that person would not need an advocate. But there are people who are either isolated or in some cases, who actually have problems with their families or even with a medical practitioner. It does happen. If you can, as it were, put yourself in that position, I wonder whether you would not feel that it is right that somebody should be able to come and ask you what your wishes were, and to act on them. I wonder if you have any comments on that.

1030

**Ms Smyth:** It really was not clear to me that the advocate did anything, except repeat what had already been told to the person who has been deemed incapable.

**Ms Carter:** As I say, not incapable, but in a position where he is vulnerable, and although the advocate may be telling the person what his rights are in this situation—as I say, the primary function is to find out what that person wants. Not necessarily what is in his best interests, because when you are an adult, you have wishes that may or may not be considered by other people to be in your best interests, and yet you feel you should have the ability to have those wishes carried out. I just leave that with you.

**Mr Wessinger:** I wondered if you might explain to me your concerns with respect to subsection 6(2) of Bill 109. If I might explain why that section is in there, it has been indicated to us by medical practitioners that they would consider many of their patients perhaps capable of consenting to a medical treatment such as stitching up a cut or fixing a broken arm, but when it came to a very

complex situation of weighing risk and benefit, say of something like chemotherapy, they would not consider the person capable. The purpose of the provision is to allow people to have more power to exercise decisions rather than to have less power. Perhaps you could explain your concern in regard to that.

**Ms Smyth:** It seems to me it is rather patronizing for a doctor to assume, "Even though I have explained this to you, I know you do not understand, so I am saying that I will make the decision for you."

**Mr Wessenger:** It is really your concern about the health practitioner being too patronizing, assuming a person does not understand and making the assumption that he would have the better judgement. But of course in that instance the person has the ability to have an advocate come in and advise him of his rights to challenge the—

**Ms Smyth:** But does the advocate have any power as against the—I think if an advocate is arguing with a doctor, the doctor would probably always win.

**Mr Wessenger:** No, let me explain. The advocate has a very limited role with respect to the Consent to Treatment Act. The advocate only has the role of advising a person of his rights to challenge the finding of incapacity. I think this is where the confusion is in respect to the advocacy. In other areas, the advocate of course has probably a much broader role. In respect to consent to treatment, it is a very limited role only.

**Mr Malkowski:** Thank you for your presentation. Your concerns were useful in helping us understand some of the problems. You were saying your concern was that the legislation gives the advocate more power than the family. Could you tell me what your concerns are about the advocate and the family, and maybe we could see where the misunderstandings are. Could you explain that for me?

**Ms Smyth:** It seemed to me that the health practitioner does not have any choice when he has declared a person incapable, except to call for an advocate. To me the first people who should be involved are the families.

**Mr Malkowski:** Would you agree then that the advocate perhaps could help the people who have no families or relatives and that the legislation would help them? The people who are vulnerable and have no families would be in need of someone.

**Ms Smyth:** I would agree with that.

#### ONTARIO ADVOCACY COALITION

**The Chair:** I would like to call forward our next presenters from the Ontario Advocacy Coalition. This is just a reminder that you will have half an hour for your presentation. The committee would appreciate it if you would hold your remarks to about 15 minutes to allow time for questions and comments. As soon as you are comfortable, could you please identify yourself and then proceed.

**Ms Fussell:** Thank you for your welcome. My name is Joan Fussell and I am the co-chair of the Ontario Advocacy Coalition. Patrick Worth is the other co-chair. He is also past-president of People First of Ontario. I know you

heard from Patrick on behalf of People First on Tuesday. Orville Endicott is the legal adviser to the association for community living, both the national and provincial organizations, and also serves as the coordinator of the Ontario Advocacy Coalition. At the back of our brief you will find a list of the 34 organizations that belong to this coalition.

Having sat in on many of the sessions over the past 10 days and in December, we have developed feelings of great sympathy for you because of the difficulty of the task you have been assigned in reviewing this legislation. In addition to the complexity of the subject matter of the bills, you are also hearing widely divergent points of view from the public interest groups and individuals who are appearing before you. If it is any consolation, the magnitude of the demands placed upon you is a measure of how vitally important this legislation is for thousands upon thousands of citizens of this province.

Some time ago, we provided each of you with copies of our brief, which proposes more than 40 amendments to the four government bills. Obviously we will not be able to discuss all those proposed amendments with you today, but we hope our suggestions may be helpful to you when you begin the clause-by-clause study of the bills after hearing the public submissions. I know several of our member groups such as People First, the Ontario Association for Community Living, the Advocacy Resource Centre for the Handicapped and the Psychiatric Patient Advocate Office, all of whom made presentations to you earlier, are counting on you to turn to the coalition's brief when you come to consider the possible amendments to the legislation. It deals with many particular points which these organizations would otherwise have had to make independently, and it contains the actual wording of proposed amendments that they, among others, have helped us to prepare.

We have proposed so many amendments because we firmly believe advocacy is crucial to the development of justice and respect for vulnerable people. We endorse the central concepts and intentions of the advocacy bill and we spent a great deal of time considering how it and the other three bills can be improved. We assume that is also your objective, whichever side of the table you are sitting on. We are really counting on you to help improve these bills but to proceed with them all expeditiously.

All three political parties are not only on the record as favouring social advocacy, but have contributed over the past five years and more to the development of the idea and have helped to bring us to where we are today. We acknowledge a particular debt of gratitude to the late Father Sean O'Sullivan, who undertook the Review of Advocacy for Vulnerable Adults in 1986 and 1987 with great commitment and enthusiasm. We believe it was because he captured the vision of what advocacy can mean for people that his report has gathered less dust than any other such document we know of.

1040

As you heard the other day, Pat Worth became a close friend of Sean O'Sullivan during that review process, and I would like to invite him now to tell you a few of the things he learned about advocacy through his participation in the

review and in the work of the coalition since People First helped to establish it five years ago.

**Mr Worth:** We in People First usually refer to ourselves as "self-advocates." If you are going to be labelled, it might as well be one you choose for yourself and one that expresses what you can do about your situation rather than one that says you have a disability. What it means to us is that we can speak for ourselves when other people deny us our rights. It also means we speak up for one another. It does not mean we do not sometimes need people who have never been labelled with a disability to support us and advocate on our behalf.

To those of us who have been involved in advocacy for a long time, the meaning of the word is not vague. You have to realize that Sean O'Sullivan did not invent advocacy. It has been around for a long time. Sean O'Sullivan was able to recognize it when he saw it, so it does have a pretty clear meaning.

Let me remind you of what advocates do. Before getting into the details, it is important to consider the broad picture. An advocate is someone who is always your ally. The advocate respects the vulnerable person and for that reason always tries to do what he or she knows that person wants. The advocate's actions consist chiefly of being a voice for the vulnerable person. The advocate will speak to the vulnerable person to provide information and clarification, but he or she will also speak to other people so they will know what the person wants and is entitled to.

What advocates do to help people can be expressed under four headings: Advocates defend the rights of the person; advocates help people get appropriate services if they require them; advocates support people so they can make decisions for themselves; advocates assist people to be connected with other people in the community who will value and support them.

People need advocates to do these things because they often cannot get people to listen to them or they do not have enough information to know whom to talk to or what they should say. Without support, they do not have enough confidence in their own abilities. They are powerless to change the things that are keeping them in bad situations.

The kind of support an advocate can give helps them to develop self-confidence. Advocates will not do things for people in a way that makes them think they do not have to do anything for themselves. Advocacy empowers people and gives them a more equal footing with those who have been robbing them of their dignity. The reason vulnerable people are vulnerable is that they are not recognized as having equal value as citizens along with everybody else.

One of the things Bill 74 does not make clear enough is that advocates must act independently. Their only commitment is to the vulnerable person on whose behalf they act. The legislation is quite strong in stating that the Advocacy Commission will be independent of the government and that it will be made up of people who have gained the confidence of the various groups of seniors and persons with disabilities across the province. But it does not say anywhere that you cannot be an advocate and at the same time work for an agency that provides other services to

people with disabilities. We think it should state that clearly.

The Advocacy Act follows Sean O'Sullivan's recommendation that there should be both paid and volunteer advocates. He called it the shared model of advocacy. Ideally every advocate would be a volunteer. A volunteer is an advocate just because he or she is strongly committed to people who are always at a disadvantage because they have a disability. That willingness to be committed to the other person as though his or her cause were one's own is a necessary ingredient of advocacy. We in the coalition know there are a lot of people in this province who are willing to do that without being paid. The need for advocacy is so great, however, that we also know we will need to have advocates who earn their living as advocates.

I said earlier that advocates will always try to follow the instructions they receive from the person who needs advocacy. This is an important principle, but it must not mean that advocacy will not be available to people whose disabilities are so severe that they cannot tell an advocate what their wishes are. These are the people who are the most vulnerable of all, and it is essential that they have access to advocates in just as full a sense as they could if they were able to give instructions to an advocate.

It is my personal belief that once a strong foundation of a relationship is being built between the vulnerable person and the advocate, the advocate comes to know the wishes and dreams of the vulnerable individual and can understand them.

If I could add to this, I know some people think that the Advocacy Act came into focus because professionals wanted it and because it seems like professionals are speaking about it. But it really came through the hearts of people who are vulnerable because of this system. We are the people who are getting tired of the system betraying us or the system locking us up and hurting us and separating us from our friends and families and society in general. We are the people who were really screaming for an independent advocacy system that we can own and that we can nourish so that we can build a foundation of advocacy. We think it is important that you give us that chance.

**Mr Endicott:** It falls to me, and after Patrick's words it is rather anti-climactic, but we did want to say a few things about the rest of the government's legislative package. We are after all an advocacy coalition. As Patrick said, advocacy empowers people. Substitute decision-making, on the other hand, unless it is arranged in advance by the individual concerned, essentially disempowers people.

One of the coalition's recommendations, which you will find in our brief, is that Bill 108 should be amended to include criteria by which to determine whether an individual has the capacity to give a power of attorney for personal care. The bill sets out such criteria only in relation to a power of attorney for property decisions. The coalition thinks the test for whether a person can give a power of attorney for personal care decisions should be based on a determination of the person's actual trust and confidence in the person or persons who will exercise the power. It should not be a test based on whether the individual could, at the time the power is granted, make all personal care

decisions for himself or herself. Where the individual's trust in those who support him or her is real, warranted and demonstrable, the law ought to make it possible for them to be his or her attorneys for personal care.

We do not have time to go over the coalition's other particular recommendations with respect to Bills 108, 109 and 110, but I do want to stress that there are a lot of them. They are found in our brief together with specific wording that we believe will improve all the bills. They are the joint work of a large number of organizations representing people in many different areas of disability and seniors. They are counting on you to find them in our brief, so they have not been as detailed in their own.

#### 1050

One final recommendation must be brought to your attention. The commencement provisions of Bills 108, 109 and 110 all say that those acts will come into force on the same day as the Advocacy Act. We have suggested an amendment that would create a two-year delay after the Advocacy Act is proclaimed into law before the other three come into effect. There are two reasons for making this recommendation.

First, as you are aware, the Substitute Decisions Act and the Consent to Treatment Act will create a number of situations in which a person who is deemed incapable of personal decision-making is to be visited by an advocate. We endorse this as a useful safeguard to prevent unnecessary guardianship or other substitute decision-making, but we also anticipate that it will exert a very considerable demand on the resources of the Advocacy Commission. We want the commission to have a chance to become established before having to meet those demands.

The second reason for phasing in the other statutes at a later date is that we believe advocacy will be such a significant new factor in dealing with the issues of diminished capacity for self-determination on the part of people who have disabilities that new statute law in relation to those issues should be open to amendments to take into account those new realities before coming into effect.

Those are our submissions. We look forward to your questions.

**Mr Poirier:** You have been here for a lot of the presentations. You have come to see me and I have told you, and I repeat it publicly, that I support the principle you are pushing for. Legislators, whether in government or in opposition, have the same concern, that the bills you want to see brought forward and put into reality solve more problems than add to the list of problems. We know—especially when you have been here for seven years, like me—that between what we start out with as an intention and sometimes even after public hearings, some horrible things can happen. You find out they complicate some aspects more than they solve.

Some of the concerns are people living with schizophrenia, for example, and some of the other testimonies where they want the Advocacy Act to empower the individual as opposed to the advocate, because the person who is supposed to be served is the person in need as opposed to the advocate.

If this is supposed to empower the person, I would like you to be able to respond to some of the criticisms you have heard and tell us how we can accommodate some of those people who are concerned about their survival, which they support in principle, but who are afraid. For example, when someone like the young person we had yesterday wants to be able to write a contract that says, "Whenever I go off my medication for schizophrenia, if I write a contract that says to bring me in there and make sure that I am given my medication no matter what I say, because what I say when I don't take my medication is not the truth and is not what I really want to say," how do you deal with that? Every coin has two sides, friends, and as we have seen, some coins are really weird. They have five sides.

**Mr Endicott:** Joan looks at me. I guess one of my responses would be that this coalition actually was responsible for a clause in Bill 74, the Advocacy Act, which requires the Advocacy Commission to include in its functions the enhancement, acknowledgement and encouragement of families. We know that families are the primary resource for people. That is the way it always should be. We do not anticipate for a moment that advocacy will change that.

As an advocate myself, not in the area of psychiatric disability but intellectual disability, I have found that nearly always when advocacy is required it is parents who come to us and say, "Can you help us?" Advocates do have resources that are not available to families: resources of information and resources of knowledge of where the pressure points are that need to be pressed in the system. We think the fear that an advocate will diminish the legitimate role of families is unwarranted, based on experience.

**Mr Poirier:** A lot of the people with schizophrenia or Alzheimer's come forward and tell us exactly the opposite. They tell about real-life situations where they have really been challenged, opposed, sidelined or whatever by so-called advocates. Hopefully with the commission and with the new independent advocates there will be more control on people doing this. I hope so. My father has Alzheimer's. I sure would not want an advocate to come between my father and me and say: "We know what's best for your father. You're stepping on your own father's toes or your own father's rights." I would really be upset. Believe me, I could share that.

We are trying to make sure that the intent of this legislation, when it translates into reality, matches exactly the intent. That is the only reason we are raising questions, not to hinder it but to make sure you do not come back to us afterwards. The problem is that once you come out with a bill, if there are some bugs in it, it is not like summer camp; you cannot call your mother and say, "Take me back," because it takes more than 3.46 days to correct the inadequacies in a bill if it comes out with some bugs in it. That is why we are worried, because if the bugs are there and the bill comes out too quickly, it is going to take a heck of a long while.

I also say this to my friends in government: Now that we know your priority list says this should be the number

eight priority, I would like to be a fly on the wall in the Treasurer's office when somebody comes forward—I do not know who will come forward—and says, "We expect this to be the financial bill, the cost of this." I think Floyd is really going to have a pink bird—flamingo—right there on the spot, and he is going to say: "Drop dead. There's no way I can afford this now." That is what I am afraid of. I told that to you when you came to see me. I said publicly, with all good intentions, we all want to see something happen. But I am really afraid of that. That is why maybe what is going to come out is not what we think may come out. Make sure you look at the opposition of people. I have invited you before. Let us know what you think the objections are and respond to them because that is important for us to know.

**Ms Fussell:** I would like to point out to you, Mr Poirier, that often people who are within the service-providing systems profess to be advocates for their patients, and many to a great extent are. However, they are also part of the system that is providing health and social services. This advocacy system is a completely different concept in that it will be independent of the health and social service systems. It will be designed by vulnerable people for vulnerable people. An advocate under the advocacy system will be responsible to speak only for that particular vulnerable person who is his or her client. It is a very different approach from what you have heard of as advocacy in the past when it is really coming from someone who is part of the delivery system.

**Ms Carter:** Thank you for your very constructive contribution to this issue. Patrick Worth has suggested that those who are unable to give instructions should nevertheless be able to have an advocate, and that is foreseen in clause 36(d) of Bill 74. I understand the view that sometimes if a person who appears to be quite incapable is close enough to another person, he can to some degree be understood. Nevertheless, the key idea of the Advocacy Act is that it is the client who is directing that the job of the advocate is to express the wishes of the client. In suggesting that, the full range of advocacy service should be supplied to those who are unable to instruct an advocate. Are we not endangering this principle? Are there not some problems there?

**Ms Fussell:** We believe the principle remains intact that, generally speaking, advocates will receive their direction only from their clients. However, if there is no exception ever made to that rule, then the most vulnerable people among us will be the ones who do not have advocates. You are quite right in that it often requires an astute advocate to understand what the instructions are that a person can make to an advocate. There still will be exceptions, however, where a person perhaps cannot give clear instructions, even to an astute advocate. On the other hand, if those people are not provided with advocacy services they are most likely to be subjected to the abuses and neglect we hear about all too often in this province; people, for instance, who are in less well-regulated institutions or boarding homes. It is just a gap that is too important to

allow to go unfilled by advocates under this act. Perhaps Orville or Pat have something to add to that.

1100

**Mr Endicott:** I appreciated Pat's remarks about the advocate, with effort, coming to understand the individual's wishes. I think that is a very important principle. If there is going to be any reference to a person being incapable of instructing an advocate, I would rather that be reworded that the advocate has not been able to ascertain what the individual's instructions were. It is going to be difficult for an advocate to develop that rapport because admittedly he or she will not necessarily have all the time in the world to develop it before some representations have to be made. I think there has to be a recognition that some wants and needs can be taken as expressed.

Patrick talked about the role of advocates in defending people's rights. The advocate can know that person has rights. He talked about services the advocate can help people have access to, and if the person is in that degree of disability there obviously will be a requirement for services the advocate may have some knowledge of that other people are unaware of, that way of understanding the person's wishes even without getting them in words.

**Mr Malkowski:** Thank you for your presentation. It was certainly very impressive. That is as usual, I should add. I just want to recognize at this point your group's contribution, the hard work you have done and your commitment in promoting the concept of advocacy and the concept of an advocacy system. I know this is not a new idea to you. It is something you have worked on for many years.

The three parties and past governments, Liberal, Progressive Conservatives and ourselves, have all spoken in support of the principle of advocacy. I know that you, Patrick, for example, became friends with Father O'Sullivan. The O'Sullivan report is something you have all spoken in support of. It talks of the need for this type of advocacy system. At this point I would like to say straight out that my ministry and my minister, Elaine Ziemba, have come up very clearly from the very beginning in saying that advocacy has to be a priority of this government. We will go ahead with this concept. I would like to say that you have certainly become our friends and that we are going to begin this process of empowerment and working with vulnerable people. This is not where things end; this is in fact just the beginning.

**Mr Winninger:** I have a brief response to Orville's points about Bill 108? I think it would be instructive to attempt to spell out some criteria for capacity to appoint an attorney for personal care as we have done in section 8 with attorneys for property. I might get in trouble with Mr Fram for saying that, since he just came in.

In addition, though, I would have some concern were the implementation of Bills 108 and 109 to be delayed for two years as you suggest, because I think advocates may have a very onerous burden on them when they—

**The Chair:** Mr Winninger, excuse me, but I advised everybody a couple of days ago. Could you please get close to the microphones? There is trouble with Hansard

picking it up and there is trouble because the people at the back of the room cannot hear.

**Mr Winninger:** It may place an unreasonable burden on advocates when they cannot point the vulnerable individuals to all the necessary directions that might involve the kind of guardianship for personal care or attorney for personal care provision that they would enjoy under Bill 108 and the advance directives for consent to medical treatment that they might enjoy under Bill 109. I wonder if you could respond to my concern in that regard.

**Mr Endicott:** Certainly the advance directives provision is something the coalition and its member groups are very supportive of, and in a sense our recommendation to delay the implementation of the Substitute Decisions Act was subject to some concern that there would be people who could take advantage of that now, for example, people with AIDS, and why make them wait? AIDS Action Now is a member of our coalition, and we asked it specifically, "Do you realize you are sacrificing something your members may wish to avail themselves of?" In the end, they concurred that these issues are too important and that the Advocacy Act has to have priority because it deals with empowerment.

Personally I think there may be things like the continuing powers of attorney that possibly could be implemented earlier, severed from the rest of Bill 108, because they really are measures of empowerment. Our concern is that so much of the other two bills are really measures of disempowerment, removing rights from people and vesting them in someone else. We feel there may be better ways of dealing with those issues than are presently incorporated in those statutes.

**Mr Winninger:** I do not necessarily agree with you, but at least I know where you are coming from.

**Mr Phillips:** Just quickly, the Advocacy Act may be very timely, because just as it is coming along, perhaps for the first time ever we are looking at, I gather, contracting services in the province, with less money being available for the services that you will be advocating. How big a role do you see the Advocacy Commission playing in advocating with the provincial government? Will that be a significant role, in your view, for adequate funding for the services?

**Ms Fussell:** We think there will be a significant role for the advocacy system to do systemic advocacy. It is inevitable that when case advocates are present in institutions and know the conditions under which people are living and the problems people are having with the systems, they will try to put on some kind of pressure to reform the systems. It is not necessarily, in our view, going to mean that the systems will cost more than they do at the present time. It may mean there will be some pressure to redirect some funding in health care and social services to be more in tune with what people really need.

**Mr Fletcher:** Just one quick question: On the implementation, you have a two-year gap. Why two years? Is that an arbitrary number?

**Mr Endicott:** I do not think it is arbitrary. It was not one that we calculated over a long period of time. I think it

is based on the knowledge that it is important that those other matters be dealt with legislatively and that we would not want to be seen as wanting to delay some action. We feel that certainly it will take that long for the Advocacy Commission to really be prepared to respond to the demands that are made and that during that period the advocacy system will create such a change—it ought to create such a change—in the situations vulnerable people face that the answers to their decision-making problems may be very different from those anticipated now.

**Mr Fletcher:** I tend to agree with you.

1110

#### CANADIAN COALITION FOR THE PREVENTION OF DEVELOPMENTAL DISABILITIES

**The Chair:** I would like to call forward our next presenter, Dr Graham Chance. Good morning. I just remind that you will be given half an hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Dr Chance:** Thank you, Mr Chairman. I have arrived somewhat breathless on a late Via train from London.

My name is Graham Chance. I am a professor in the department of paediatrics at the University of Western Ontario. I am a member of the Canadian Paediatric Society bioethics committee and a consultant to the foetus and newborn committee of the Canadian Paediatric Society, but I am appearing here on behalf of the Canadian Coalition for the Prevention of Developmental Disabilities, a group I have chaired for the last 12 years.

The composition of the coalition is that it represents both professional bodies and lay bodies concerned with children's health, particularly the wellbeing of children and the prevention of disabilities, recognizing three levels of prevention, not simply primary prevention, and recognizing the fact that much prevention is possible through the Advocacy Act.

The concern of the coalition is primarily with section 15 of Bill 109, and I understand other people have been represented who also have concerns with section 15 of Bill 109 and the explanatory notes. In particular, as a coalition concerned with children's health, obviously the concern is in regard to research with children.

As I explained, the coalition concerns itself with children, disabled or otherwise, that they should in fact be given the optimal opportunity to reach their full potential. As worded at present, the ambiguity of section 15 is of concern to the coalition, recognizing almost certainly that the intent was good, but the ambiguity of the statements in section 15 could lead to interpretation that the bill prohibits research. I recognize that this has been discussed before with the committee, but I feel a continued discussion of this section is very important to children as a group that has the inability to give primary consent and that has been, in the majority—until they are 16 in this act—unable even to write in advance, to seek consent, to state their intended views.

The concern of the coalition is primarily then in relation to the first part of section 15, "A procedure whose primary purpose is research." As I said, the presumption is that there is intent for a neutral legal position but the words, taken in isolation, could in fact be interpreted as "prohibit" rather than "does not authorize."

The reason for these concerns relate to past experience in relation to research and children, and I am referring particularly to the reaction that occurred after the Eve decision of the Supreme Court of Canada. You may recall the Eve decision was concerned with a 25-year-old incompetent adult woman whose mother wanted to protect her against pregnancy and for whom a court decided hysterectomy would be the appropriate approach. The Supreme Court of Canada rightly ruled against that as an appropriate approach to this particular situation. Throughout his judgement, Mr Justice La Forest was concerned essentially with this woman's capacity to reproduce. However, the Supreme Court judgement became widely interpreted, much more widely interpreted than one suspects was originally intended, and was eventually to include children's research and non-therapeutic research in children.

The submission I have supplied has given several appendices. Appendix 2 is an abstract taken from the Medical Research Council of Canada guidelines of 1987. If I can direct you to that appendix, in the fourth paragraph it says, "The conditions under which children can volunteer for non-therapeutic interventions of no benefit to them are contentious." In a reference at the bottom of the page it refers to "Re Eve 1986."

The problem is that children, being unable to consent, were to be precluded from therapeutic research but especially from non-therapeutic research, and advances that were open to adults and other members of society were to be precluded from children. The consequence of that, of course, is that we have an unethical situation in regard to a segment of the population.

Lawyers interpreted the Eve decision very rigidly. I have simply abstracted for your interest three papers written by Mr Gilbert Sharpe, by Professor Dickens and by Professor Solomon from the University of Western Ontario. Gilbert Sharpe's paper, on the second page in the last paragraph, recognizes, "There are obvious implications for other non-therapeutic interventions, such as medical research, the removal of tissue such as bone marrow from a healthy child to help a sick one, and so on."

I have two pages from Professor Dickens's article, appendix 3. Professor Dickens stated, "Problematic procedures that courts may be cautious to approve that parents may authorize include male circumcision, vaccination when not legally required, and children's involvement in non-therapeutic medical research." I mention the first not to say that it is a vitally important act on the male child but simply to point out that some acts can lead to rather ludicrous results.

He goes on in the second paragraph on page 116 to state, "Children's involvement in non-therapeutic medical research, for instance, by separate blood sampling or a more invasive or risky procedure, may be impermissible."

Finally, in the paper by Professor Solomon, on the second page, the third paragraph, it says, "The current law appears to prohibit all non-therapeutic interventions based on substitute consent, regardless of how trivial the intrusion may be or how great the benefits."

Having seen then what transpired following the Eve decision and what thoughtful academic lawyers and thoughtful physicians concluded in regard to therapeutic and non-therapeutic research, the coalition was concerned to read section 15, particularly paragraph 1, referring to research. Being concerned that the ambiguity of the statement in isolation—I stress "in isolation," because if one looks at the whole act through and through, perhaps it is not so ambiguous—as occurred with the Eve decision, it could prevent valuable procedures which are necessary for children's health and wellbeing.

Examples abound in the past where therapeutic procedures were brought in without adequate research. A particular concern we had at the time we were considering the Medical Research Council guidelines was the recognition of the continued need to accept therapeutic privilege in relation to innovative procedures. Those guidelines condoned—and one would agree that innovative procedures should be available to children—the actions which were innovative but precluded adequate research to prove that those, though innovative, were in fact effective. If it is impossible to undertake adequate research to prove that procedures are effective, then children are in danger of being subjected to procedures that are inadequately proven and yet are brought into standard practice.

#### 1120

This has been very widespread in past medical history. Many examples abound but I quote one in the paper I gave to the Canadian Bioethics Society relating to a cause of blindness in children. We nowadays have a major advance in newborn care, the use of a material obtained from lungs of cows or manufactured, which is reducing mortality and morbidity rapidly in low-birth-weight infants. That procedure, that medication we use, could not have been, could not have been researched at all, if section 15 were interpreted as prohibiting rather than not authorizing.

In considering section 15, others have suggested that it should be dropped from the act. Perhaps that is the right thing to do with it. Perhaps it could be better worded to be absolutely certain that the intent of the act is not to include research as one of the measures at all considered in the act. Not being a lawyer, not having read Professor Dickens's submission to the committee, I made a suggestion for rewording in the brief I have given to you. Having read Professor Dickens's submission, I see that I was obviously wrong with regard to the second and third parts of section 15 in that what is being discussed there is illegal in fact. But none the less, the coalition would be very grateful to see some rewording that would clarify that this is not intended to inhibit the development of research for children. I think that summarizes the situation.

**Mr Malkowski:** I would like to thank you for your presentation. We have heard from a variety of groups throughout these hearings, many of them disabled consumers

themselves. One of the concerns they have raised is the issue in relation to the medical community on the tendency for the medical professionals to try to turn disabled people into "normal people." I know that a lot of what you are talking about is prevention of disease or things that are actually therapeutic in the sense of combating illness, but those treatments that are actually trying to "correct disabilities" seem to have been a concern within the disabled consumer movement.

Dr Oliver Sacks, for example, has come out and said it is very important that members of the disabled community who are interested in being involved in medical training or in redefining the roles of health professionals should be the people who also get involved in medical research, sort of a promotion of disabled people becoming involved as medical researchers, in some ways to change the slant of some of the research. Could you comment on the concerns the disabled community has raised and also on that issue.

**Dr Chance:** The coalition, I should stress, is widely representative. Represented on the coalition is the Canadian Association for Community Living, the Canadian Cerebral Palsy Association and other disabled groups. Essentially when I started, I stated that the coalition is indeed concerned with the three levels of prevention. We recognize, for example, that the tertiary level of prevention is the prevention of society disabling people by calling them "handicapped," those who are already disabled. So the concerns we have are general.

I think it is not a particularly wrong desire of the medical profession to try to help people to health. Health can be very broadly interpreted. A person with severe cerebral palsy can still lead a very constructive, healthy life. I have worked closely with a cerebral palsied person involved extensively in research.

I am addressing this group as the chairperson of the Canadian Coalition for the Prevention of Developmental Disabilities rather than as a physician who is indeed a researcher and a professor of paediatrics, and in that capacity as chairperson, I am trying to be concerned that what can be offered to children, disabled or otherwise, should be offered to them as it is offered to adult persons.

**Mr Malkowski:** Then you would agree that it is important for medical professionals who are involved in medical research to also have complete information, understanding both the positives and negatives of specific disabilities so that they are actually fully informed of the various viewpoints out there.

**Dr Chance:** I think it is very important that as medical professionals we are fully informed. From the point of view of those disabled, I think certain points in this act are undoubtedly very beneficial. The central concern is not with the act or the intent of the act as a whole, but with the wording of one particular section.

**Mrs Cunningham:** I always say representing London, Ontario, has a couple of great benefits, and one of them is the great advice we get. I am sure my colleague Mr Winner shares my pride in that. We certainly are pleased to see you here giving us this kind of advice.

My colleague Mr Wilson has advised me that this is not the first time he has heard this concern and that he has said if the government is not prepared to come forth with either some kind of an amendment to the wording or to drop it, as you have suggested, we would certainly be doing that and hoping for its support. My guess is that they are going to do something about it.

Perhaps legalistically we cannot come up with new wording. How would this concern, certainly as the government has presented it in this bill and your own concern, be dealt with if it was not in the legislation at all? How could we be reassured that the concern that is presented because of this wording is going to be dealt with in today's world without this legislation?

**Dr Chance:** I think one has to state that today's world, for the medical researcher, is one of very careful supervision. I think Dr Lowy went through the procedures with the committee that a research application would undergo in regard to the application, the consideration by both scientists as to its validity and by an ethics committee as to its ethical validity. In our own university, for example, a university bioethics committee considers all applications. Hospital departments will also consider all applications.

I cannot say the surveillance research is put to these days is foolproof; nothing in this world is foolproof. But to view it as impossible to undertake certain very minor procedures to try and benefit children, to try and ensure that children are as healthy as they can be, if that becomes prohibited, that is dangerous for children.

I think medical researchers recognize the past. Anyone who has read a book describing Nazi doctors entitled *The Nazi Doctors* would recognize the evil that can transpire from the medical profession uninhibited. Particularly clinical researchers, but also basic researchers, are very carefully supervised in their research endeavours. The process is, for some, regarded as tedious, but it is vitally important.

**Mr J. Wilson:** I may be in some conflict on this. My brother is a researcher, a PhD in the department of zoology at Western and teaches at the med school there. He has been at me about this on several occasions. The government, though, will tell you, because this has been raised a number of times by very learned people, that the wording of section 15 is that it simply does not authorize research, but it would claim it does not prohibit it. The parliamentary assistant to the Minister of Health, Mr Wessinger, has told us that really the status quo remains. We will keep pursuing this.

I guess this is more of a statement, because I am not really satisfied with that answer. It is clear this is included in a section with two other procedures that are clearly illegal under the current law and that there is a problem there. At the very least, perhaps we could get the government to move it out of that section. Really it is just a comment. To back up what my colleague said, we are very concerned about it also.

**Dr Chance:** It is not only a coalition, who are not lawyers, but very learned lawyers are indeed concerned with its wording—the potential for ambiguous interpretation suggests that in some way it has to be adapted.

**Mr Wessenger:** I would just like to make clear to you, Dr Chance, that certainly the intention of the legislation is not to change the existing law at this time with respect to the matter of research. I think it is very important that there be nothing in the act that either expands the right or detracts from the existing law, so I would like to make it clear that is the intent of the legislation. We feel the existing language works well. If clarification is needed, it will be looked at, as I have said to other groups.

I thought I should advise you in case you are not aware—because I think you have an interest, obviously, in this area—that Professor David Weisstub has been asked to do a study on this area. I do not know whether you are aware of that.

**Dr Chance:** Yes, I am aware of it.

**Mr Wessenger:** I suggest that maybe you should have copies of the terms of reference for the study he is going to do. You might wish to make presentations to Dr Weisstub with respect to this matter, because he is going to be making recommendations, I understand, some time in the summer of 1993.

**Dr Chance:** Yes, thank you, Mr Wessenger, I am proposing to do just that. I think it is important, though, that within the act as it is worded at present, nothing is stated about Professor Weisstub's work and nothing is stated regarding the Minister of Health's reassurance that research is a different topic to the act. The act itself, as it is worded at present, has confused many people, who are concerned. People who one would anticipate would be able to read legal documents carefully and interpret them appropriately have become concerned by the wording.

**Mr Wessenger:** Let me just say, Dr Chance, that even lawyers have different opinions on wording, so it is not only the non-lawyers who are sometimes confused.

**Dr Chance:** I recognize that.

**Mrs Cunningham:** So you are just going to drop it, Paul, are you not, so we do not have to worry about it?

**Mr Wessenger:** No, it would not be dropped, because that would expand the whole area to have no limits. I really think it has to be looked at. Is there any ambiguity in the existing language, and if there is, is there a way of correcting that ambiguity?

**Dr Chance:** Thank you. I think many of us will be delighted to learn that. Just to pick you up on the statement that even lawyers have different ways of wording things, that is precisely the concern of the coalition. The response we saw to the Eve decision was to word a very important document for most researchers, the Medical Research Council's guidelines, such that children were potentially precluded from beneficial research. We do not want to see that happen again.

**Mr Wessenger:** I can understand that.

**The Chair:** Dr Chance, on behalf of the committee, I would like to thank you for taking the time out of your busy schedule to come and give your presentation this morning.

I would like to call forward our next presenter, Josephine Wdowiak. If she is not here, this committee will recess for five minutes to give her a chance to show up. This committee stands recessed until 11:40.

The committee recessed at 11:33.

1143

**The Chair:** I call this meeting back to order. Since our next presenter has not shown, we will now recess until 1:30 this afternoon.

The committee recessed at 1143.

## AFTERNOON SITTING

The committee resumed at 1341.

HOSPITAL FOR SICK CHILDREN,  
MEDICAL ADVISORY COMMITTEE

**The Chair:** I call this meeting back to order. I would like to call forward our first presenters, from the Hospital for Sick Children. Good afternoon. Just a reminder that you will be given a half-hour for your presentation. The committee members would appreciate it if you would keep your remarks to around 15 minutes to allow time for questions and comments. As soon as you are comfortable, could you please identify yourselves for the record and then proceed.

**Dr Goldbloom:** My name is Alan Goldbloom. I am the associate paediatrician-in-chief at the Hospital for Sick Children. I am accompanied by Dr Françoise Baylis, on my right, who is a bioethicist on the staff of the Hospital for Sick Children and has been involved in the preparation of our brief.

I would like to thank you for the opportunity of coming here today and speaking to you about Bill 109. My brief is presented on behalf of the medical advisory committee of the Hospital for Sick Children. I realize that you have heard and may be hearing other presentations from other representatives of the hospital. While there may be some overlap, I hope that our information will complement that which you will be hearing or have heard.

Bill 109 has an admirable goal. It attempts to codify regulations regarding consent which currently reside in several different acts and also to ensure the rights of those who may be mentally incapable of giving or refusing consent of their own accord. Our concerns do not rest with the motives behind the legislation. Instead, they relate to the design of the legislation itself and to the enormous problems that might result from its enactment. We are concerned that some of the proposed safeguards which may be appropriate for some populations could actually serve as barriers to health care for other patient populations.

Throughout the bill there is reference to those who may be mentally incapable of consenting to or refusing treatment. While it may be that this was intended primarily to cover the mentally handicapped, the very elderly population and those whose acute medical problems render them incapable of decision-making, it also includes virtually everyone under the age of 16. Thus, it has great significance for all providers of child health care.

It is generally accepted in our society that parents have the authority and the duty to act in the best interests of their children until those children reach the age of 16. Any stated age of maturity is by definition rather arbitrary, and there may be many 14- or 15-year-olds who have the maturity to participate in decision-making regarding their health. The bill seeks to acknowledge this right, but establishes a procedure that is unwieldy and may in fact be a significant roadblock to adolescents seeking care.

Indeed, adolescent clinics across North America have worked hard to ensure the rights of young teenagers to

seek and obtain medical care and advice of their own accord. Thus, teens with problems such as sexually transmitted disease, drug addiction and emotional problems can seek help on their own. Many of these children would not seek or receive the needed help if they had to involve their parents or if they had to submit to any kind of bureaucratic process to determine their capability to make decisions. We therefore agree that this population needs to be empowered, but we would maintain that it is already empowered under existing law, which permits them to seek help of their own accord.

Unfortunately, the broad brush of this act puts all individuals under the age of 16 in the same category. Thus, it may be acceptable for a 15-year-old to refute his or her incapability of consenting; it is quite another thing for a five-, six- or seven-year-old. I realize you have already been presented, in the brief from the Ontario Hospital Association, with examples of some of the ludicrous situations that might arise if the bill were applied literally to the 5-year-old child who objects to a needle. Indeed, most pre-teen youngsters can be counted on to object to most treatments or procedures that might cause pain.

I further understand it was not the intent of this legislation to interfere with such treatment when agreed to by a parent. If so, then the wording must be clarified to reflect the true intent. Without such a change, we would be faced with an unwieldy bureaucratic nightmare, calling in advocates for every child who says no.

There are, however, some circumstances which are not so clear-cut. For example, a 10-year-old child has leukaemia. We now know that 75% of childhood leukaemia can be cured with appropriate treatment, but the treatment is sometimes unpleasant. One of the unpleasant side-effects of chemotherapy is temporary hair loss. Upon hearing this, one can imagine a child adamantly refusing treatment. The parents want treatment to begin as soon as possible in order to have the best chance at preserving this child's life. Again, the health care provider must inform the child of her right to an advocate, and if she chooses to take advantage of this, an advocate must be called in as prescribed in the legislation.

This solution to the problem involves bringing in an outsider at a time when a family is under maximum stress and is attempting to deal with some of the most painful and difficult crises that any family can encounter. This is a time when a family unit needs to be nurtured, supported and strengthened so that it can deal with the situation. Perhaps I can share with you how we would handle such a problem under existing legislation.

First, I can tell you that we very rarely impose a treatment on such a youngster. Children in these circumstances are usually terrified, as are the parents. They need time, they need to talk, and this is the time when we involve our multidisciplinary team, which may involve social workers, child psychiatrists, child life workers, nurse specialists and physicians. Such problems can and do get worked through in this fashion on a daily basis at our hospital. In other

words, as far as children are concerned the system works. I am tempted to suggest, "If it ain't broke, don't fix it."

If we took this child's initial objection at face value we would, according to the legislation, have to inform the child of her right to an advocate. This is probably the worst possible time to invoke the bureaucracy by calling in an advocate. To do so automatically establishes an adversarial and destructive relationship between the child and the parents and perhaps between the child and the care givers.

In dealing with the older child, such as a 14-year-old, the legislation seeks to empower that individual through the availability of advocacy. Again, I think you should know that it is our current practice not to treat a seemingly capable 14-year-old over his or her objections. However, true empowerment for that child does not derive from provision of an advocate at the first sign of any objection. Instead, I believe empowerment comes in the form of support, listening and counselling of that individual in order to help him or her work through a difficult decision-making process, a process that may take several days or weeks to come to completion. Unfortunately the bill, taken literally, would negate the most natural and biologic of advocacy or protective roles: that of the parent for the child. It also ignores the fact that child health care has its foundations in advocacy for children.

There are, of course, situations where the parents' wishes are not in the best interests of the child. Again, I could use the example of a child with a treatable disease but whose parents may object on the basis of personal or religious beliefs. The existing law, the Child and Family Services Act, already covers this situation, in allowing us to identify a child in need of protection. Furthermore, the child welfare agencies that are empowered by this act have extensive experience in dealing with these situations, and we do call upon them quite regularly. I see no need for any other advocate in this situation.

1350

Of particular concern to health care providers is section 9, which states, "In determining a person's capacity with respect to a treatment, a health practitioner shall apply the prescribed criteria and follow the prescribed standards and procedures."

This vague reference to "criteria" and to "standards and procedures" is not further defined or clarified. Will one set of criteria apply to all situations and all age groups? Who will determine the criteria, standards and procedures? Once determined, a care giver might be sued on the basis of not having followed such criteria to the letter of the law. The wording is dangerously loose.

Again, I believe we have a system in place regarding children that functions well now. Each practitioner uses his or her professional judgement in determining a child's capacity on a daily basis. We use that judgement as the basis for determining how we explain things to children or in determining whether we should treat a 12-year-old without a parent's consent.

I believe that section 9 should read, "In determining a person's capacity with respect to a treatment, a health practitioner shall use his or her professional judgement and training." Obviously the health practitioner must still be

responsible for his or her judgement and must be able to defend it, as we must for any type of care we deliver.

Subsection 16(8) presents another concern for those of us in health care. It suggests that if two parents are in conflict over an issue of consent regarding their child, the public guardian or trustee should be called in. Again, the legislation would appear to deal with a family in conflict by invoking rather legalistic mechanisms.

In current practice we would see this as a family that needs help and we would mobilize the resources available in our multidisciplinary team to help a family work through a problem. This is a very common situation, yet it almost always gets resolved in a far more supportive and therapeutic way than the legislation would prescribe. In the rare instance in which resolution is not achieved, we still have the children's aid society or other child welfare agency available to us as a resource and we would see no need for a public guardian or trustee.

I also want to touch on the subject of research in children. I realize that research is not the major focus of this bill, but the topic becomes relevant by virtue of its specific exclusion in subsection 15(1). If subsection 15(1) stays in the bill in its present format, it will be subject to misinterpretation and has the potential to stop all clinical research involving children in Ontario. At first glance, this may appear to be an act that attempts to protect children; however, I firmly believe that this section of the act may do children long-term harm. It says, in effect, that adults are allowed to benefit from research but children may not.

I would like to explain that the subject of research in children is one which immediately causes people to react negatively, as it usually evokes rather ghoulish images of children being subjected to painful or noxious treatment as some form of human guinea pigs. This stems, I believe, largely from a general ignorance of clinical research and of the preventive measures that are already built into the system now in the 1990s.

To clarify this I must give you some examples. First, I would point out that all research protocols undergo critical review by multidisciplinary ethical review committees before they are approved. These are not rubber stamp approvals. Strict guidelines are enforced, research that might do harm is not permitted, and potential benefits must be clearly stated. But I think I can clarify with a practical example.

About four years ago a major study was conducted by paediatricians in Toronto in collaboration with the infectious disease division at the Hospital for Sick Children. It involved a common problem, and that is the way children react to immunizations. Any of you who is a parent will know that after baby shots sometimes children get a fever and are irritable for a few hours or a couple of days. These immunizations are standard and they are required by law. It is very common practice to give infants acetaminophen, also known as Tylenol or Tempra, if fever or discomfort should develop.

Some of our paediatricians wondered whether giving acetaminophen just before the immunization might prevent discomfort. A study was done using several practices in Toronto and involved giving some of the children acetaminophen and giving others a placebo just prior to the immunization.

In order to embark upon this study, an ethical review was completed, approval was obtained and every parent had to sign a form indicating that he or she consented and had to be fully informed about the study. Hundreds of babies were enrolled. The results have been published and indicated that indeed the reaction could be prevented with a dose of acetaminophen. That has been disseminated and is standard practice now by many paediatricians across North America.

I think you can imagine how difficult it would have been if an advocate had to be called in to sign each consent form at each well-baby visit in a paediatrician's office after sitting through a hearing to determine whether it was appropriate for the infant to participate.

Much research in children involves issues of acute care, and then there are practical problems of involving an advocate. For example, in every paediatric emergency room we see children with asthma who arrive in considerable respiratory distress and with difficulty breathing. We usually administer medication immediately, and this is given through a mask; the child inhales it. There has been some discussion recently about whether more frequent doses of the same medication might give greater relief.

Even this manoeuvre, if we are to study it, requires ethical review and informed consent before we can begin. Because it is at the time of acute treatment, there is no time to involve any kind of formal advocacy process. If it were felt that an advocate had to be involved, this kind of research in acute care would simply cease and our current state of knowledge of all acute treatment would remain for ever at the 1992 level.

Research is often very closely linked to treatment, particularly in serious diseases. We are always looking for improved outcomes in childhood cancers, liver disease and kidney disease, and often treatment itself is part of a multi-hospital research protocol involving new or experimental agents that have been shown to have significant promise. Most parents have been eager to participate in the hope that they will help to find new and better treatment for their child's ailment. Survival in childhood leukaemia was almost zero 30 years ago. In 1992 it approaches 80%. If it were not for research in childhood, we would still be at zero. The dramatic improvements in the survival of tiny premature infants can be attributed directly to research involving that very population of infants. Informed parental consent is always obtained, but there would never be enough time to involve a government-appointed advocate during the few minutes between the time of birth and the time treatment must begin.

Thus, when it comes to research, I think those who draft the legislation need to become cognizant of the existing safeguards and review processes which are stringently enforced not only by all teaching hospitals but also by all major granting agencies. Somehow, research seems to be portrayed with a negative connotation, as something from which children must be protected. We do not see it that way. We see research as an enormous benefit, but one which will be denied to children if the act is passed. The results of research in adults is generally not applicable to children. Section 15 therefore has the potential of stagnat-

ing all paediatric research in Ontario and must be altered. We realize that a separate review, the inquiry on non-therapeutic medical procedures on behalf of mentally incapable persons, will be addressing these issues in detail, and we will be making submissions to that inquiry.

In summary, I hope that I have been able to demonstrate to you that those of us who have dedicated our careers to children's health are deeply concerned about the potentially harmful effects of this legislation and urge that it not be passed in its present form. I would just summarize by saying that we support the submission made by the representatives of adolescent medicine at the Hospital for Sick Children two days ago, which questions the arbitrariness of the age 16 limit; that in ordinary circumstances we feel the parent should be the advocate for the so-called incapable child; that the existing child and family service agencies throughout Ontario are in a position to provide further advocacy when needed, and finally, that section 15 on research needs to be altered.

**The Chair:** Thank you. Questions and comments?

**Mr Wessenger:** Yes. Thank you for your presentation. Just to clarify the situation, I assume what you are advocating with respect to the matter of age is that it be left at the common-law position where it is determined whether the child has the capacity or not without any presumptions. Is that correct?

**Dr Goldbloom:** That is correct.

1400

**Mr Wessenger:** Second, with respect to the matter of research, I would like to assure you there is intent to change the existing law with respect to the matter of research, and if that needs clarification, it certainly will be done.

Last, with respect to the matter of a family dispute in subsection 16(8), just looking at that section I would suggest to you that there is nothing in that section that would prevent you from attempting to resolve the problem in a non-emergency situation by using your resources to try to get agreement. I do not see anything that would prevent that approach. I certainly would encourage that approach. It ought to be encouraged before you go to another step.

The only comment I would make with respect to your saying we already have a mechanism under the Child and Family Services Act is that the mechanism involves a court application, which could take more time than the procedure under this act, which merely requires the consent of the public trustee. I am just suggesting it might be more expeditious as it is set out under the act. I agree there is a mechanism existing, but it would seem to be more expeditious and not involve court procedures. I would just ask you to comment on that.

**Dr Goldbloom:** I guess what has not been clear to me in reading through the bill is the timeliness or the urgency with which one must respond to such a situation in terms of calling in an advocate. Does it have to be immediate when a conflict is observed or when someone says, "No, I object," or is there in fact time to try to work things out in the way we normally would do now? That is not clear to me in the act. Françoise, I do not know if you had some other comments about that as well.

**Dr Baylis:** No, I think that was our concern. It reads right now "demonstrates a wish," and it is not clear to us when one demonstrates a wish either to refuse or to consent. If that means saying no or if it means pulling back, then there does not seem to be a time frame built in for us to use existing mechanisms that might take quite some time. Sometimes dialogue takes, I would say, at least a week or so. At what point do you call in the advocate? It seems to us in our reading that there is not an interim period allowed for.

**Mr Wessinger:** I think really that calling the advocate only relates to the child and does not really relate to the parents at all; you would not be calling in an advocate where the parents disagreed with respect to treatment. I think it would only be the situation where a child who was capable of expressing an opinion would be—maybe I will ask you this as a supplemental follow-up question. It has been suggested that perhaps only children over a certain age might have the right to seek an advocate, because it is obvious you do not want an advocate called in for a four- or five-year-old. I think that is quite clear. It is certainly not the intent of the legislation to have an advocate come in and advise very young children. On the other hand, if a 13-year-old wishes to make his or her own decision and there is some doubt about whether that child has the capacity, then I think it is to give the child perhaps in that type of area a right to call on an advocate. I am wondering if there is a minimum age you would think would be appropriate for rights advice to a child.

**Dr Goldbloom:** I have difficulty with a specific age because of the tremendous range of maturity we see at any given age. We see 13-year-olds who may be behaving more like an eight- or nine-year-olds and similarly some very mature 11-year-olds. Obviously any stated age becomes very arbitrary, and I guess that is why I have some difficulty with the process. I would rather see a mechanism whereby we could use existing regulations to identify a child who, in a situation of true conflict, needed some help, and I think perhaps a mechanism working through existing child welfare agencies, for example, that are supposed to speak for children in need of protection, if you will, might be a better route than going the advocacy route.

**Mr Wessinger:** I think it should be made clear that certainly it is the intent of the legislation, and always has been the intent, that a capable child should be able to make the decision concerning his or her medical treatment. That is certainly a principle of the legislation. As I said, we may need some improvements to clarify that and to make it work better, but certainly that is the basic intent of the legislation.

**Mr J. Wilson:** Thank you, Dr Goldbloom, for your presentation. This really is a follow-up to Mr Wessinger's line of questions. You mention on page 4 that the presumption is that calling in the advocate would create an adversarial situation. We have had debate on both sides of this issue. Have you had any experience in that, or is that just your reading of the act? Some people have explained that because the advocate needs all these powers, we assume there is some sort of adversarial system, but we have also had many other people saying no, that is not what advo-

cates do and they are simply there to give rights advice and speak on behalf.

**Dr Goldbloom:** To answer your first question, no, I have not had specific experience with it. Ordinarily I do not see advocacy as automatically being an adversarial position. What I do see in this situation, in the situation of children, is an advocacy interfering in the normal family structure, and that is where I see it becoming possibly adversarial. For example, I would have no problem with the idea of an advocate speaking on behalf of an adult who was incapacitated. I see nothing adversarial about such a relationship. What I do see as a potential problem here is interfering with what we accept in our society as a normal family structure. I would rather maximize our utilization of those structures and relationships and work them out as best we could, because I think the long-term outcome will be better.

**Mr Malkowski:** Thank you for your presentation. We have heard several presenters from the disabled community and also some parents who have disabled children. Their experience is that the doctors give them information, in terms of medical research or the kind of experimental treatment that might happen. Often they ask what treatment is going to be included, what are the risks involved, what are the potential side-effects, and from their experiences, they have not been fully informed by the physicians. What they say is: "Oh, they'll be okay or there'll be an improvement. Just sign the form." Then of course they go ahead and sign the form, but that is not what happens in reality.

I would like to ask you, do you think it is important that the physicians are responsible to fully inform what the benefits as well as the possible side-effects are before they consent to treatment? Do you think doctors need to be accountable for fully informing the patients?

**Dr Goldbloom:** Thank you for your question, Mr Malkowski. I certainly do. The answer is very simple: I think physicians must be fully responsible for informing about all aspects of the treatment, both positive and negative, and I cannot support in any way any episodes where that has not occurred. I hope that in our hospital in particular, through our ethical review team, which has physicians and laypeople, we have been able to ensure a mechanism that scrutinizes such research extremely carefully.

**The Chair:** Dr Baylis and Dr Goldbloom, on behalf of this committee I would like to thank you for taking the time out this afternoon and giving us your presentation.

**Dr Goldbloom:** Thank you.

#### CITIZEN ADVOCACY WINDSOR-ESSEX

**The Chair:** I would like to call forward our next presenter from Citizen Advocacy Windsor-Essex. Good afternoon. I would just remind you that you will be given a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Mr LaBute:** Good afternoon. My name is Dean LaBute. I am vice-president of Citizen Advocacy Windsor-Essex. I

am accompanied today by our managing director, Shirley Jarcaig. Mrs Jarcaig will make the presentation of our submission to this committee. Following that, we both would welcome your questions.

**Mrs Jarcaig:** We of Citizen Advocacy Windsor-Essex are a local voluntary advocacy organization incorporated in 1975. We as an organization would like to contribute our individual point of view to this new legislation.

We commend the government for taking the initiative to introduce legislation that, for the first time anywhere, supports disabled consumer involvement and responsibility. We feel there is potential to do much to address the needs of vulnerable people in this province with this new legislation. The effort made by the government to have direct contact with advocacy groups in consultation over the drafting of this bill is also appreciated by all of us in the advocacy movement.

The following concerns are being presented to this committee, based on the years of experience we as an organization have had in providing advocacy in our community. The Citizen Advocacy organizations of Ontario figured heavily in the O'Sullivan report on advocacy for vulnerable adults.

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Our concern is that the concept of long-term advocacy provided in the context of an ongoing relationship which our organization practices will be eliminated by legislation which promotes short-term problem-solving. It has been our experience with short-term situations that the individual who requires short-term advocacy has repeated need for it as situations arise. If the individual lacks a support network of family and/or friends to assist them with the problems of daily living, he or she is likely to be subjected to potentially abusive situations on a fairly regular basis. Abuse is not always intentional, it is more likely to arise as a result of neglect, lack of education or awareness, or falling through the cracks of a system that has criteria for everything. We find that the one-to-one long-term matching is far more attractive to volunteers than short-term situations. The relationship carries rewards for both individuals. It promotes the dignity and acceptance of the vulnerable person. Short-term problem-solving does not bring the same sense of satisfaction, and it is far more difficult to recruit volunteers for that task.

Over the years, we have proven to our funders that advocacy services can be provided by members of the community for a relatively low cost. The quality of that service and its residual benefits of integration, community awareness and community ownership make it superior to what can be provided by paid professional advocates. Self-advocacy and systemic advocacy have been outgrowths of our program which we encourage and assist.

Consumer empowerment is evident in all aspects of the organization. The majority of our board of directors and committee members are vulnerable adults. We have accomplished these goals through years of painstaking effort and education.

Many individuals who have suffered perceived abuse from the social service system do not trust the individuals

employed by that system. Paid advocates may be regarded in the same light, particularly if those individuals were previously employed in the social service sector. Trust does not develop simply because someone says, "I am an advocate." Trust is developed over time, and certainly not on the basis of the amount of training received or the number of degrees acquired. Although paid advocacy may be necessary to meet the many needs of a large population because sufficient numbers of volunteers may not be able to be recruited, in our eyes it is an inferior form of advocacy. Limited funding will also limit the number of paid advocates available. Volunteers will need to be used to prevent overloaded paid advocates from providing minimal, ineffective advocacy because they are spread too thinly to devote the time required for each individual.

We have heard the term "empowerment" used a great deal, but professionalism contradicts the meaning of this new social service catch word. Our concern is that professional advocates will consider the volunteer an inferior worker, particularly if they have never worked with volunteers or are not required to do so in their positions as advocates. Perhaps some of that perception will be relieved if those people paid to advocate are also of the vulnerable population. Seniors, physically handicapped, former psychiatric patients can be and have been powerful advocates for their own populations. They are also far more likely to be aware of the problems that arise and would be able to readily gain the trust of a vulnerable person. It is hoped that a disabled advocate would also identify strongly with the person for whom he or she is advocating. The advocate is never in control, it is always the person whom he or she is representing that has the power, whether the advocate agrees or not.

Our organization's experience with capable volunteer advocates who are also disabled has been very positive. Able-bodied paid advocates should not be hired solely on the basis of academic background and experience. A sensitivity to the people they are dealing with will be essential. We feel that the number of paid advocates should not determine the extent and quality of the service provided.

Community-based programs are not only more sensitive to the needs of the people in the community, they are more action-oriented and cost-effective. Bureaucracy, top-heavy with administrators who dictate actions from, in our case, 200 miles away will only encumber a system, making it slow, inefficient and expensive. Regional offices have a tendency to form a network that requires a tremendous amount of paperwork and not a great deal of identity with the community in which it is located. If this advocacy system is to be successful in accomplishing its goals, then each community will have to have some responsibility for it.

The present wording of the legislation does not eliminate social service providing agencies from housing advocates. We feel that without such wording, the possibility of conflict of interest will inevitably result. This has been illustrated countless times by the situation presently experienced by adult protective service workers for the developmentally handicapped and other advocacy programs housed in services. An advocate must be able to work

independently and only in the best interest of the individual or vigorous advocacy will never result.

An advocate housed in a service providing agency would be identified with that service simply by his or her physical presence. The individuals seeking assistance will think of the advocate as a service provider and the advocate himself would be exposed to the service provider mentality on a regular basis. Even if the service housing the advocate does not have a direct conflict, it is still part of a system that the advocate may need to confront at any time. Services do not like to antagonize each other. Each service agency does not wish to damage relations which could benefit agency funding, interaction or cooperation. The good of the agency always takes precedence over the good of the individual. An organization that solely deals with advocacy takes an understood role that sets it apart from service provision.

Our organization also advocates for children and families. We are concerned that many children who are in need of advocacy will not have access to that system. Present legislation may offer legal protection to the child. Our concern is that non-legal issues may not be addressed. This would particularly be true of children who are in care facilities. When the family is not present to take an active role in advocating for its child or lack the skills, interest or knowledge to do so, the child is far more likely to be neglected or abused. Service providing agencies, care providers, school systems etc, will do what is in their own best interests and may lose sight of an individual child whose needs differ from the norm. Without strong advocacy these children become lost in whatever system they happen to be involved.

We are also concerned that organizations such as ours will no longer be allowed to assist children and families of children when they are in need of advocacy. If rigid guidelines are developed as to who can advocate and for whom, much of the sense of community involvement and ownership regarding advocacy for the vulnerable may be lost. If alternatives are not available to children, must the advocacy system turn them away without recourse?

Another concern we wish to express is for those vulnerable individuals who cannot give direction to an advocate. They would not be included in the advocacy system because they would not be capable of giving consent. These people are those who are most likely to be in need of advocacy. A public guardian 200 miles away will not ensure that those most severely disabled are receiving proper care or that their rights are respected. Suspected abuse could not be investigated or addressed.

There is a danger of an advocate abusing an individual as well, but the risk is worth taking when no other foreseeable alternative is possible. Such advocates may need to be given stricter guidelines and require more monitoring with greater accountability. Our experience, however, in dealing with this population of vulnerable adults has been a very positive one.

All three pieces of legislation being considered by this committee require an advocacy system in place. If all this legislation is passed at the same time, who will provide the advocacy required for consent to health care and guardian-

ship prior to the establishment of the advocacy system? The advocacy required in the guardianship and consent to health care is quite technical and will require advocates with specialized training. We would suggest the advocacy bill have an opportunity to be implemented before the other two pieces of legislation go into effect to avoid the difficulties and confusion that may result.

We appreciate the opportunity to present our point of view to this committee. Our organization is fully committed to advocacy for vulnerable people and we are glad to see that the government of Ontario is willing to make that same commitment.

**Mr Poirier:** Thank you for coming forward. It was a most interesting brief. There is always a great debate between voluntary and paid advocates; the norms, centralized or decentralized. For each system, no matter which way you cut the cake, you can list advantages and disadvantages, I am sure. The perfect system does not exist, just like the perfect MPP does not exist, nor will it ever.

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**Mrs Cunningham:** Who are you speaking for?

**Mr Poirier:** I am speaking for the humble one, Mrs Cunningham. Thank you for making my day. There it is.

I know a lot of volunteers do some excellent work and whatever. What I am worried about is that maybe in some cases the volunteer advocate, with the training that may be required—I am sure they get involved with very complex issues, very complex laws and whatever. I am just wondering about care for the client, the person who needs the services of an advocate. How do you feel about the downside of this, on a voluntary basis that would decentralize like that? We must admit there is a possible downside to that: the training, the uniformity of the training; responsive to what authority, should there be a problem that the client is not served well? What is your feeling about this? I am sure you have discussed this.

**Mrs Jarcaig:** Yes we have. With regard to the training, in our own organization we do ongoing training. For short-term, problem-solving types of situations the person probably would be receiving more training, but I would recommend it be more experience oriented, learning how to advocate through doing it, with assisting someone who is either paid or has had a lot more experience doing it. Getting a degree or taking a bunch of courses is not going to make an effective advocate. It is going to come from the experience of actually advocating for that individual. That is where they are going to learn to become effective advocates. For the short term I think there probably is a lot more contact than with whoever is running the program, be it paid advocates or however the system finally works out with us. We have coordinators in our program and we are the ones who act as follow-up and support to the advocate. If they have a problem or an issue they feel they cannot handle on their own, they call us up and we try and lend them the information, support, whatever is necessary for them to get through that particular issue or problem, whatever it may be.

**Mr Poirier:** Do you have some paid advocates? Do you have a mix?

**Mrs Jarcaig:** What we have are voluntary advocates, a coordinator of the program and myself. We also advocate on behalf of people as well. We only get involved with the voluntary relationships when the advocate and the partner feel they want us to be involved. It is all directed by the partner; that means the person with the disability. They determine what kind of advocacy they want, how they want to proceed, and then the advocate will follow through on the partner's wishes.

**Mr Poirier:** If the bill came into effect tomorrow morning, or soon, do you feel you could rely permanently, long term, on the supply of volunteer advocates, quantity-wise and qualitywise?

**Mrs Jarcaig:** This is the only reason we feel paid advocacy probably should be involved too. We cannot guarantee there will be an infinite number of volunteers available for all situations. I do not think that is realistic. We need to acknowledge the fact that there will be certain forms of advocacy and certain situations that develop that probably a paid advocate should definitely handle for various reasons.

**Mr Poirier:** So you could see like a hybrid system.

**Mr LaBute:** It is our contention that through incorporation in the legislation of the recognition and adoption of long-term advocacy, we find that an excellent entry level for volunteers, under the coordination and direction of our paid advocates, our professional staff. With their guidance and direction it has worked well. We are going on 18 years for this organization in Windsor. If it works, it should be recognized. If it can work in Windsor, it can work in Oshawa, Kingston, Toronto etc.

It is our contention that long-term advocacy and the use of volunteers should be an intrinsic part of Bill 74 and that when the commission is allowed to come up with its operating parameters and the code of ethics and guidelines for implementation of the program, our needs and those of the people we are there to assist will be met.

**Mr Poirier:** All these volunteer advocates would have to adhere to these codes of ethics and parameters and whatever?

**Mr LaBute:** Absolutely.

**Mrs Jarcaig:** They essentially do already.

**Mr Poirier:** I am sure.

**Mrs Jarcaig:** We do have a very strict philosophy within our organization and when people agree to be volunteers in our program they agree to what the purpose of the organization is. It is the empowerment of the partner, the empowerment of the disabled person.

**Mr Poirier:** Fair enough. I was sure your volunteers would meet those requirements. I was wondering about the loose Exocet missile somewhere in Ontario that would do a lot of harm to the image of voluntary advocates. It only takes one of those to really ruin the image sometimes.

**Mr J. Wilson:** Thank you for your presentation, the gist of which I gather is that you are in favour of advocacy and you promote long-term advocacy on a volunteer basis—which I think is tremendous, by the way. I gather you are sort of looking to the legislation, the legal docu-

ment, and to us to maybe put some safeguards in to make sure you are not left out when the new commission—

**Mrs Jarcaig:** To make sure we are not eliminated, quite frankly.

**Mr J. Wilson:** That is the concern? It is that strong?

**Mrs Jarcaig:** I think it is for all Citizen Advocacy programs. We presently do get government funding and United Way funding. They will say: "There's an advocacy system in place. Whatever the government decides is sufficient advocacy should be reasonable, so why does an organization like yours need to exist?"

**Mr J. Wilson:** It is a good point because we have asked, in the process of putting it together, literally hundreds of groups that received grants and that claimed to be advocates. My view is that no matter how well intentioned this legislation is—that is what we hear from the government, that it is well intentioned—something will have to give in the system. In fact, I will go to the point of asking groups, "Are you willing to give up your grant in your organization to fund the new one?" because we just cannot in good conscience add another layer of bureaucracy and expense to the taxpayers.

**Mr LaBute:** We are not asking for another layer of bureaucracy at your expense—

**Mr J. Wilson:** I know you are not.

**Mr LaBute:** —but rather a blending, a hybrid of the two. We do believe it will work. In fact, we have proven in Windsor that it works, both for short-term systemic and also long-term advocacy.

**Mr J. Wilson:** I agree with you. How do we make sure that what we are saying right now does not happen, that you are not eliminated? Can you even think of any particular clause in the legislation we should be adding to? Perhaps it would be better to delineate actually who is on the Advocacy Commission. I do not know.

**Mrs Jarcaig:** We are part of the Ontario Advocacy Coalition. In their submission I think they made it very clear that they feel the majority of people involved on this commission should be vulnerable people from organizations representing vulnerable people.

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**Mr J. Wilson:** That should ensure—

**Mrs Jarcaig:** That should hopefully be a start there, yes. It will be up to the commission. We do not want to put too many loopholes or too many things in there that would hamper the commission in doing its job. We realize it is not going to be an easy, one no matter what.

**Mr J. Wilson:** I agree, but as a legislator I do not want to set up an arm's-length commission to do whatever it wants to do, either, and leave it up to the cabinet to make up regulations. We have almost done that with human rights and ombudsmen and all that. Then we do not fund them properly and we end up with huge backlogs. For a lot of people we create a lot more problems than we are solving. It is all well intentioned. If you read the debates when many of these other boards and commissions were set up, the intentions of my government at the time were wonderful.

They made great speeches, but it does sometimes boil down to a question of resources.

**Ms Carter:** Thank you for your submission. I think really you are very close in spirit to Bill 74, certainly the way I see it. I do not see in what way there is anything in Bill 74 that would prevent long-term voluntary advocacy. In fact, it actually says in subsection 3(2), "This act applies in respect of advocates who work, whether on a paid or voluntary basis, for the commission or in community programs operated under this act."

It is also stated in subsection 6(1), "A majority of the members of the commission shall be persons who have or have had a mental or physical disability, illness or infirmity."

We are not looking at setting up something very bureaucratic, rigid and professional. We are looking at something that will be arm's length from government, very consumer oriented. You have both hinted in what you have been saying that some kind of two-tiered system might develop where volunteer advocates who could maybe spend a long time with a particular client, or practically all their time, be it their friend or relative, could nevertheless call on the extra expertise of the paid advocate. Do you think that is the way it might develop?

**Mrs Jarcaig:** That is what we are hoping will be the case, because unfortunately, what happens with social services is that the volunteer does the Joe jobs for the professional staff who do not want to do those jobs, and there is almost like a competitiveness: You do not want your volunteer to be too good because he might show you up. That should not be the case here. This should be very community based, community oriented.

**Ms Carter:** That is certainly how we envisage it. I think that is how it will develop.

**Mrs Jarcaig:** That is what we are hoping for.

**Ms Carter:** We have also heard some groups say that advocates interfere with family support systems. Can you tell us what kind of experience you have had with that?

**Mrs Jarcaig:** We found the very contrary to that. Because there is a long-term relationship between the two individuals, there is a relationship that also develops with the family. There is a trust that sets in, and very often the advocate is an assistant to the family in helping with various issues where the family feel they are being left in the lurch to deal with them on their own.

**Ms Carter:** There again, we can kind of see a two-tiered system. We could see the advocates maybe helping parents who have vulnerable children and who need a little support and guidance in dealing with them.

As I say, I do not see a split between the way you want this to turn out and what is envisaged in the act.

**Mrs Jarcaig:** I think our main concern with the act is that it really looked like the act was just to do very short-term, problem-solving types of things. It really was not looking at advocacy as being done on a long-term basis in a relationship such as we have in our own program.

**Ms Carter:** Maybe the only other problem we have with what you are saying is that you do emphasize, as the act emphasizes, that it should always be the person, not the

advocate, who is in control. It is his or her opinions that the advocate should be carrying forward and acting on, yet you do want advocates rather than guardians to assist people who are not capable of making their own decisions. Can you explain how you reconcile that?

**Mrs Jarcaig:** We have people in our program, very dedicated advocates, volunteers in our program, who advocate on behalf of people who are living in institutions and who are not capable of giving any kind of consent or response, but who certainly are deserving of having proper care, deserving of knowing that there is someone in the community who cares about what happens to them and who they are as people. That is something that, if you had an official guardian, just would not happen. You have an office there. You have people who will deal with issues if they are informed about them, but what we are talking about is somebody who is there to recognize that person as a person.

**Mr Wessenger:** Thank you very much for your presentation. I think you are filling in some of the gaps for me in understanding how the advocacy situation is in Ontario. First of all, I would like to know—maybe you cannot answer this—how much of Ontario is blanketed with these advocacy services such as yourselves. Do you have any idea?

**Mrs Jarcaig:** I think there are presently something like six Citizen Advocacy programs in Ontario. We are all functioning at different levels because of funding problems or issues or whatever you might call it. I believe the Ottawa program made a presentation here on Monday.

**Mr Wessenger:** Would you suggest that it is a good model to have for all of Ontario?

**Mrs Jarcaig:** That I cannot say. We are all very independent of each other, all the Citizen Advocacy programs in Ontario. We all go out and get our own funding. We are all based on the needs of our own communities. What might be good for Windsor, and the policies that Windsor sets, might be somewhat different from what Ottawa sets and what Ottawa does in response to the needs in its community.

**Mr Wessenger:** For instance, how many volunteers would you have in your program for providing services?

**Mrs Jarcaig:** Right now we have between 40 and 45 long-term relationships, and then we do advocacy for between 20 and 25 people on a short-term basis. But we have a very limited staff and very limited budget etc.

**Mr Wessenger:** You may not be able to answer this question, but I think you are suggesting in effect a two-tiered system, for your area anyway. Your organization would continue to do what we would call primary advocacy, and then you are looking at the paid advocate as probably taking up either some of the systemic role or perhaps the very difficult cases that you cannot pursue, that you do not have the resources to pursue. Is that what you are sort of looking at?

**Mr LaBute:** We are asking that they be housed together, as they are with the Windsor Citizen Advocacy. It is a working together of the two forms of advocates, working for the benefit of the vulnerable people we deal with on a day-to-day basis.

**Mr Wessenger:** Of course you see it working on a cooperative basis.

**Mr LaBute:** Absolutely. Housed together, not as a separate bureaucracy but within the same structure; a division of responsibilities up to a certain point. The volunteers are involved. When it reaches a point where they need to bring in the professional advocates or the paid advocates, they would be brought in, as would other resource people who would assist on an as-needed basis.

**Mr Wessenger:** This is another question you may not be able to answer. In terms of numbers of advocates, with your present system in operation in your area, would you see a need for a large number of paid advocates or would a few be all that would be required?

**Mrs Jarcaig:** That is really difficult to determine. I do not see that this system is really going to be able to have huge numbers of paid advocates. There is just no way you are going to be able to afford it. There is no way it is going to be able to happen, so you have to rely on the resources within the community. I would say that the majority of advocacy should be done by volunteers if at all possible.

**Mr Malkowski:** I just want to clarify your concern about the Advocacy Act, saying that it will not include volunteer advocates. Is that what you are concerned about?

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**Mrs Jarcaig:** No. What we are concerned about is that it does not appear right now to be particularly volunteer-based. It looks right now like it is something where you would have a system of paid advocacy, and maybe volunteers would be something that would be sort of a sidelight of it. But it appears that the emphasis is on paid advocacy.

**Mr LaBute:** What we are requesting is that equal recognition be given to both paid and volunteer advocates and that they both have a role to play in the advocacy program.

**Mr Malkowski:** I just wanted to clarify that, because I think the Advocacy Act is clear that it includes both paid and volunteer advocates. The Advocacy Commission itself will be at arm's length from the government and will develop regulations to make sure it fills in the gaps where it feels services or resources are missing. So I am just wondering if you would agree that the goal should be a complete system that would include both paid and volunteer advocates.

**Mr LaBute:** Absolutely.

**Mr Malkowski:** Okay, I have a last point of clarification. You were concerned about children not being involved. I do not think the Advocacy Act says anything about preventing advocacy for children. There is nothing in the act that stops advocacy for children.

**Mrs Jarcaig:** Were there not age limitations placed there?

**Mr LaBute:** That was our understanding. I believe 16 was the age we understood.

**Mr Malkowski:** Just to clarify, what I am saying is that we are not stopping children from being involved in the advocacy process. We are not stopping that. Perhaps Trudy could clarify this point.

**Ms Spinks:** Yes, I think what Mr Malkowski is saying is that the Advocacy Act does not preclude existing groups that provide advocacy services to children on a voluntary basis from continuing to do so.

**The Chair:** Thank you, Mr Malkowski. Mrs Jarcaig and Mr LaBute, on behalf of the committee I would like to thank you for taking time out today and coming and giving us your presentation.

**Mr LaBute:** Thank you, Mr Chairman and committee members.

MADELEINE HONEYMAN

**The Chair:** I would like to call forward our next presenter, Madeleine Honeyman. Good afternoon. Just a reminder that you will be given a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Mrs Honeyman:** Thank you. I am Madeleine Honeyman of Ottawa. I am speaking as a consumer-caregiver and long-time advocate on behalf of Alzheimer's people and their families and older people generally. I thank the committee for allowing me to speak. Perhaps you would give me permission to speak on the advocacy part of my presentation first, because we have been talking about advocacy and perhaps what I have to say on this will enlarge what we have been talking about here.

First of all, in the Advocacy Act, Bill 74, I am concerned, and I know that other people who are working in the same area as I am are concerned, that it says the majority of the commission will be or have been disabled. If this is the case, it effectively closes out people who are cognitively impaired, and we would respectfully ask how they are going to be represented on this commission, because they cannot represent themselves.

Because it also states in this that the commission shall provide advocacy services and will offer training programs, I am very interested in what has been said here today about volunteer advocates. The province is really covered with volunteer advocates. That is one of the major things that associations like the Alzheimer Association of Ontario and the Parkinson Foundation do, although they are not formalized in being called advocacy groups.

My concern is how you are going to train these professional, paid advocates. Who are they going to be? There is nothing in any of the material that I received—I have read it many times—that even suggests what qualifications and educational background these people are going to have or what peculiar and particular training they will have to answer to the sensitivity of situations that occur with Alzheimer's people and other cognitively impaired ones.

It says in subsection 7(1) that we must "comply with the standards and procedures established by the regulations." This is what the advocates and assessors are going to have to do, but there is nothing along with this that suggests who these people are going to be, how they are going to be regulated or how they are going to be evaluated. One of the things that really surprised me throughout

all of these bills is that there was no suggestion of evaluation for any of these people and how they would operate within the community.

Will the same standards apply for volunteer advocates as for paid advocates? How do these fit in together? Certainly that is what you have been hearing from these people. One of the major things advocates are supposed to do is help families or persons who are vulnerable bring about structural changes. This is why we have a real concern about older people, particularly older people with cognitive impairment, being included with disabled people who may be able to think and speak for themselves, because they will not be able to do anything about structural changes. Again, we need people to be able to speak for them, because many structural changes need to be made on behalf of these people.

My biggest concern about the advocacy program is that it seems—I do not want to be too harsh on you or on the legislation—to have become adversarial rather than friendly. I understood that this was a social advocacy, not a legal advocacy. We seem to have put aside O'Sullivan's report, *You've Got a Friend*. He wrote a lot about what advocates should really be. I think that has been lost completely in this new material we have received. If we are going to use professional or paid advocates for people with diseases or conditions like Alzheimer's in institutions, they are going to have to be friends, they are going to have to be people who have some contact with these institutions before the occasion occurs in which an advocate is needed.

Old people generally are rather on edge about strangers coming in and telling them what to do or advising them about anything. I think we have to look at two different methods of using paid advocates, because you are not going to have enough to serve everybody, and that they be a special kind of people for persons with Alzheimer's and others of a like kind, that they be friendly advocates who come in and visit and become known to people before they are needed, where there are no informal advocates in place, and that they be available to families.

We talk a lot about families of small children. They may be very vocal about what happens to their children. Old men and women taking care of an old man or woman are often quite outside the legal or adversarial system and do not know how to advocate on their own behalf for the person who is vulnerable. This is, I believe, a recommendation that should be made by everybody, that some of these advocates should be able to help families know how to work the system. I do not mean it in that way, you understand; I am being a little harsh about that.

I am very concerned about the training and qualifications of the advocacy people. I am also concerned about their going into institutions and more being said about how they have permission to go in whenever they want to look at records. I know some groups of vulnerable people are very keen on this. In dealing with older people, we are not at all interested in that. We feel there might be a possibility of reprisals from people on staff against the person. In speaking about that, all the acts seem to have talked a lot in the preambles about looking after people, and particularly older people in the community as well as in institutions,

but I am afraid you lost track of that in this legislation before you came to the nitty-gritty. It always seems to be in the institutions.

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Since we have been advocating for a long time with people to say that institutions are not all bad, and may be a better place than a home for some people, it is unfortunate if the idea that comes out to the general public is that we are trying to get people in institutions and institutional care givers, because that is not quite fair. I think we have to be very careful about that when we are talking in what I see as a very adversarial way. The power of advocates has to be looked at to limit it, because we always have to keep in mind that they are social advocates.

If I may now go back to my general comments and the definition of "vulnerable," which I do not think is adequate, when it names generalized groups I think we have to remember that older people are not a homogeneous group by any means and that we have to specify what we mean by a vulnerable older person. I even heard a speaker here lump all older people together, saying "old people." I am old and perhaps I am senile, but I am not demented. We have to be very careful that we are not saying all old people are vulnerable, because it simply is not true. That comes into all the things we are talking about in these acts on consent to treatment and substitute decision-making. We must remember that some old people, very old people, are quite capable of making their own decisions. We must not become paternalistic about this.

I think almost everybody who has spoken to you in the last couple of weeks has spoken about the inability, from our point of view as consumers, for all of these bills to come into being at the same time. It is absolutely essential that the Advocacy Act be passed first so that all of these people can be trained and commissions and advocacy groups can be put into place before the others are even attempted. I would even like to see some of this being projected and tried out in certain places in the province to see how expensive it is going to be. It seems to me this is going to be an enormously expensive operation.

Another thing about older people is that in the preamble it quite definitely states that these acts cover "seniors," whatever a senior is, and people with Alzheimer's disease, but that is the last you hear of them all through the act. They just seem to have been lost from then on. I notice that palliative care and advocates for palliative care people are not mentioned at all.

There is a great deal said about assessors and assessments, but it is not clear to me who these assessors are going to be, how they are going to be trained and how they are going to explain to people who do not understand a simple sentence, a simple word—how they are going to explain to these diminished people what is meant by an action that is to take place. How can these people possibly be trained to look at all these areas?

The assessment is to be done by health practitioners. Please tell me what a health practitioner is. Is it a doctor, a health care aide or somebody in between? It seems that the act is suggesting that almost anybody can make an assessment, yet if you reread Weisstub, you will see that he said,

"There is no reliable generic diagnostic test of capacity to consent." That is after a thick book and many years of working at trying to figure out what capacity was. We are referring of course particularly to vulnerable older people and more particularly still to Alzheimer's people.

My particular concern in all of these acts is the power of attorney for the person. Some years ago, back in 1982-83 I was involved as the beginning person in getting a change in the Powers of Attorney Act for estates back in 1982-83 so that that power became a continuing power and not one that could become null and void when a person became incapacitated. So I am really surprised and disappointed that now you are considering, which I think is a wise thing to consider, that this power for the person be linked to mental capacity. I see no reason in the world for this to be.

If a person gives a donation of a power to his family or someone who is close to him to make decisions or consent to care on his behalf, he did it with the full ability of his own mind to make this decision. Why you would have to wait until an emergency to get this power validated boggles the mind. It denies the right of the person to make this decision. It may in fact deny their civil rights under the charter, because as it stands now it says that I can give to my daughter a power of consent to speak for me in points of care for my person, but until my daughter or my son sees that I have really gone bonkers—and they are probably more likely to see it than anybody else—then they have to apply for assessors to come in and assess it to see if I am capable. I may be having a really good day and they will say that of course this person is capable. That is the way this thing operates.

It is not always capable or incapable. It is up and down and up and down. That has to then go to the public trustee and guardian to be validated, to say: "Now this woman has lost her marbles completely and this can go into place: The other person can make a decision." It is arrant nonsense, my friends, because in this time—what time frame are we looking at? One month? Six months? In all this time I may go in and out of capacity, have a great many physical disabilities and need urgent medical treatment, yet my daughter is not allowed to make these decisions even though I gave her this permission.

It seems to me that you have erred in trying to protect the person too much. I suggest that this act be implemented as soon as possible with validation immediately. As long as the person stays compos, he can take this privilege or power away from the person. But to have this validation take place at some future time and assessors who do not even know the person come in just does not make much sense. It would be so difficult for families to cope with this, to even understand what the legislation meant, that I predict they just would not bother going through it. They will continue as they are, muddling along the best way they can. If they do go through with it, it is going to cost them a lot of money. The government is prepared to pay for it. As a taxpayer, I do not want to have to do that. It is just going to be a more expensive procedure than a family now going to court to get a committee, and that was the one thing we hoped for, that this would be a simple operation.

I will just make a quick comment about section 76 in Bill 108. It orders a person to submit to an assessment. Those seem to be very strong and harsh words. I read this over many times and I simply could not find where it explained to my satisfaction at what point you would have to be when someone would come and order you to submit to an assessment. I do not know whether this means when you are in a situation of abuse. Abuse is also mentioned in older people but nothing much is said about it. I hope it would include help for people who are being abused without making it mandatory that abuse be reported, but that some mechanism be set up so that different regions of the province could deal with abused older people satisfactorily and that there be some place for them to be moved to out of their home or that the abusing person be moved out of their home.

I am not going to say anything about guardianship, although I have a lot of opinions about it, but you heard from Melane Hotz last week, a woman whom I have been on many ad hoc committees with. She really spoke for me and others in this matter and knows a great deal more about it.

The one other matter that seems perhaps too simple to speak about is information and education. This is an absolute must at your earliest convenience, to find some simple way to get information out about these acts, how people can access them; an advocate, for instance. We have said a lot about that today. All older people should receive some information, a small pamphlet written very simply and sent out with their old age security cheques or something like that. They should also be printed and posted in every institution that has older people in it in Ontario. By sad experience, although I have tried to build up care facilities, they very seldom inform families and the people living there about such things as the redirection of health care, for instance.

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This is a reiteration of what I said before. Although in the preamble it states that these acts will refer to people in the community and in institutions, that seems to also have been lost track of as the pages go on. In Ottawa at least, the number of institutionalized older people has dropped from almost 9% to just over 5% in the last six years. So there are a lot more vulnerable people in the community than in institutions, although that may be where your paid advocates would have the greatest work.

Thank you very much.

**Mr Kwinter:** Mrs Honeyman, I just want to congratulate you on your presentation.

**Mrs Honeyman:** Thank you. You are just being nice to me because I have a fancy hat.

**Mr Kwinter:** No, I am being nice to you because I think you make a lot of sense. Through personal experience I have lived through many of the concerns you have expressed, and I agree with them. I just think you should be commended for taking the time to present a very thoughtful and very practical presentation. I just wanted to let you know that.

**Mrs Honeyman:** Thank you. I appreciate that. I always think that members of the Legislature are just like me. They need things simple or we do not understand them. No insult intended, but just because this is what we really understand. This is what really distresses me about all of the work that has been put into these acts. They are so convoluted that even people who have been working on it since before it was called the Fram report—I had to read it about five times before I even understood what some of the material meant.

**Mr Poirier:** Like Mr Kwinter, I think it is extremely important that somebody like you, who is an advocate, who is working close to the people who are supposed to be served by this Advocacy Act, came forward. What you saw in the act and the complex nature I really appreciate. I was listening with much interest to what you had to say because we are here to make sure that the principle of the act, when it finally becomes an act, translates into something that is graspable, something that you have more answers to than questions on. So I am glad that you came forward, and it is not because you have a hat—I love your hat; it is great, by the way—but I am glad you came forward and—

**Mrs Honeyman:** That is my equality hat, you see: a man's derby with a woman's feathers on it.

**Mr Poirier:** All right, good. We are birds of a different feather ourselves so we appreciate it. Thank you very much.

**Mrs Honeyman:** Thank you very much.

**Ms Carter:** You have raised a lot of good points here, and I just want to comment on a few of them.

First of all, you worry that the qualifications and education of the advocates are not laid down in the act. I think that was a deliberate omission because the commission is to be at arm's length from government and we wanted to leave a lot of that kind of decision to it. So what we have here is provision for the setting up of an advisory committee which will select the people to be on the commission, and then they will go on to make a lot of these decisions. Under section 15, which says who is to go on this advisory committee, we have paragraph 15(1)3, "organizations representing persons 65 years of age or older," and we also have paragraph 15(1)6, "organizations representing persons with a neurological disability, illness or infirmity such as autism, Alzheimer's syndrome or traumatic head injury."

Having said that, we did have a delegation here previously that suggested that more people aged 65 or over should be on this body, although they are already provided for. My answer to that, speaking as somebody who is not 65—but I am not that far off it, either—is that you said yourself that older people are not a homogeneous group, and a lot of them, after all, do not have any kind of disability or vulnerability. Since we are trying to define those who are vulnerable, to say that older people as such have a place in that category could be seen as an ageist concept, saying that just because people are older there is something wrong with them. Do you agree with that? Does that not make sense?

**Mrs Honeyman:** Oh, absolutely. I just want to make very clear that old does not equal vulnerable and that we must be very sure. I read that part over again and

I hoped it meant what I think you meant it to mean, but I am just afraid that—what shall I say?—more outspoken groups of younger disabled people etc may be pressuring the commission to go on these advisory boards and that the other people to speak for the cognitively impaired, the truly vulnerable older people, will be forgotten.

**Ms Carter:** Except that older people belong to all the other groups just as much as any other age group does.

**Mrs Honeyman:** They may.

**Ms Carter:** Yes.

**Mrs Honeyman:** I do not care whether it is young people speaking for the cognitively impaired as long as there are people on there who are concerned about that particular group, who are perhaps the most vulnerable. I was interested to hear the doctor from the Hospital for Sick Children. Old vulnerable people, particularly with Alzheimer's or any other dementing illnesses, are almost the same to look after as children. It is almost the same thing that is occurring. Do you see what I mean? There usually is somebody to speak for them, but not very well informed, so they need some help.

**Ms Carter:** Thank you. You also commented that the guardianship procedure under the new legislation will be more trouble and more costly than the present system, so I would like to call on Stephen Fram to comment on that, please.

**Mrs Honeyman:** I did not say it about guardianship; I said it about substitute decision-making and particularly the power of attorney for the person.

**Mr Fram:** Hello, Mrs Honeyman.

**Mrs Honeyman:** Hello.

**Mr Fram:** We have corresponded over the years through various ministers. On the validation procedure: First, I want to make it clear that under consent to treatment, although it is unclear and we are looking at making it clearer in revision, when the health practitioner finds that the person is incapable the attorney for personal care will be able to make the decision without any validation.

The second part was that validation is really the defining of someone incapable of making a decision. It is a great concern some people have had that a power of attorney for personal care should not become a trap; that is, the very existence of a document like that will lead care givers to start talking to your attorney instead of you. You know very well that the tendency is to talk to the person standing up and not the person in the wheelchair, even though the person in the wheelchair may be very capable of telling you where to go—

**Mrs Honeyman:** And they do too.

**Mr Fram:** The idea behind validation is that we should have an objective assessment of a person before that comes in as an ongoing power.

**Mrs Honeyman:** I cannot disagree with you more. You obviously know that. I understand the problem of the legal community on this. If it stands the way it is written it is just going to be a bonanza for lawyers, because if families get involved in it, it is going to cost them money to bring assessors down if they have not named assessors in the power. It may rebound to a bad result for the person

who has given the power because he or she may have ups and downs. You know as well as I do that they are not always cognitive, they may have bad times and, as I said in my presentation, they may go through a period when they definitely need that person they have given the power to to make a decision for them right then, but if they have to write off for somebody to come and validate it, the person may have recovered from that situation and have not been treated properly. I find that very difficult.

1510

**Mr Fram:** I think that goes to the first issue. On the consent to treatment situation, it does not need to be validated. It is only where the power is going to be ongoing. It is consent to treatment that usually requires a quick answer. On the other situations, you can afford to wait till a good day for a decision. There are not that many decisions that have to be made in people's lives that other people have to come in until it is an ongoing situation, other than care decisions, medical decisions, dental decisions, those kinds of things that are addressed in the Consent to Treatment Act.

**Mrs Honeyman:** Then you, in your usual eloquent way, have simplified this so much that there still does not seem to be any need for validation, because almost everything that came along, according to what I am hearing you say, comes under consent to treatment.

**Mr Fram:** Right, except for things like a transfer in facilities, moving out of the community, the big stuff.

**Mrs Honeyman:** Yes.

**Mr Fram:** That is really what we had in mind.

**Mrs Honeyman:** So you are really talking about moving them into a care facility out of their own home against their wishes. But people are doing that all the time now.

**Mr Fram:** That is why we want to make sure that at those points people are not just pushing them around.

**Mrs Honeyman:** I have a better opinion of people than you do.

**The Chair:** Thank you very much. We cannot get into too much of a debate on this.

**Mrs Honeyman:** I guess at that we will leave it, but I thank you for your clarification.

**Mr Wessinger:** I do not need to say anything except to confirm that what Mr Fram said is correct: the power of attorney for personal care does not need to be validated in order for the health practitioner to act on it.

**Mrs Honeyman:** For the consent. Oh, I recognize that, but nevertheless I am still very confused about the other. I hope it does not happen if it is going to be expensive for the people.

**Mr Poirier:** One of the first things you mention, and I got so sidetracked by what else you were saying, that the need for training—I agree with you that with voluntary people and all the good faith and all the excellence of the work surely there must be some need for training.

**Mrs Honeyman:** Absolutely.

**Mr Poirier:** Would you be able to expand on that? Have you thought about what might be necessary?

**Mrs Honeyman:** I can only come to the simplest thing I know about: the advocacy we do with Alzheimer's and have done since we started the society 12 or 13 years ago. We advocated on what we had learned with people with Alzheimer's themselves. We knew how to help other people deal with the people and advocate with the government and other institutions for the best care possible for these people, including legal care and the change in the power of attorney to be a continuing one. So I am questioning not the training for specific groups like that, which learn it from the ground up and enhance it by reading and so on, but for the professional, paid advocates, how they are going to learn that and who is going to teach them and what qualifications they have to have to begin with to be able to deal with such a sensitive issue.

**Mr Poirier:** Do you think there would be a need for further education of the volunteer? Could that be beneficial to the volunteer? Do you see it as optional or what?

**Mrs Honeyman:** Yes. If you are going to set up a good training program for the professional advocates, I would hope that would be sent out to every organization that did advocacy on the simplest level, as we do it, or the middle level like these people from Windsor do it. They should know what you were planning and perhaps they could feed in to you some things that would be helpful.

**Mr Poirier:** So the volunteers would have a choice to take some, if not all, of the courses for the training of the professional ones, right?

**Mrs Honeyman:** Yes, right; that is, if you get a good training for them.

**Mr Poirier:** Okay.

**Mr Malkowski:** Thank you for your presentation. You mentioned that advocate services would be only for institutions, but I just would like to clarify that. I want to assure you that the Advocacy Act does provide advocacy for vulnerable people who are in the community. It is not only for people in the institutions.

**Mrs Honeyman:** Thank you. I understand that.

**The Chair:** Ms Honeyman, on behalf of this committee, I would like to thank you for taking the time out and giving us your presentation today.

**Mrs Honeyman:** It has been a pleasure to meet you all. Thank you very much.

CANADIAN MENTAL HEALTH ASSOCIATION,  
KITCHENER-WATERLOO CHAPTER

**The Chair:** I would like to call forward our next presenter, Loren Calder.

Good afternoon. I just to remind you that you will have half an hour for your presentation. The committee would appreciate if you would keep your remarks to about 15 minutes to allow time for questions and comments. As soon as you are comfortable, could you please identify yourselves for the record and then proceed?

**Mr Calder:** I am Loren Calder. I am a parent living in Kitchener-Waterloo and I am a university professor. I am here to talk about the mental health aspects of the proposed

Advocacy Act, Substitute Decisions Act and Consent to Treatment Act.

I am supported in my presentation by a consumer, John Martin, a university student, who has recovered from a very serious active mental illness and some recurrences. I am also accompanied by Ken Parsons, a parent and retired school teacher who has been an advocate for his son, who has suffered from severe mental illness for 20-plus years.

We have prepared a presentation that we have agreed to. I intend to read it for you. These are recommended changes to Bills 74, 108 and 109. They are unanimously supported by the Kitchener-Waterloo Family and Friends, an affiliate of the Canadian Mental Health Association's local chapter.

We, the undersigned, are members of a subcommittee of the advocacy committee of the local chapter of the CMHA who have been assigned the task of analysing the mental health impacts of Bills 74, 108 and 109. We are speaking today as the parents of individuals with severe mental and emotional illness—schizophrenia and manic-depressive disorders—or individuals whose condition has been controlled by medication, psychotherapy and psychosocial treatments.

We note that decades of investigation by research scientists and practising psychiatrists have failed to produce precise knowledge about the causes and treatment of this catastrophic illness. We feel little would be gained by our attempting to define these illnesses here. On the basis of years of personal experience, however, we can categorically state that these illnesses are real and that their most horrendous characteristic is that they deprive their victims of sound reason and judgement in those phases of the illnesses marked by acute psychiatric disorder or psychosis.

Many victims in this phase of their illness lack insight and are completely unaware of the acuteness of their condition. In such a phase they are very vulnerable to serious bodily harm and even death, precipitated by their incompetence. They cannot provide even elementary care and maintenance for themselves and are often involved in potentially violent confrontations with the police and others. Because of this loss of judgement, we feel significant changes must be made to the proposed legislation. Our recommended changes are detailed below.

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Bill 74, the Advocacy Act:

1. The act's broad definition of "vulnerable person" needs to be amended to take into account the loss of reason and judgement which characterizes victims of severe mental and emotional illness in their acute psychotic phases.

2. The act's assumption that higher-functioning consumer-survivors can adequately represent the interests of the most severe victims is flawed. It should be amended so that parents who are primary care givers and professionals are actively involved in the advocacy process, especially at the level of the Appointments Advisory Committee and the Advocacy Commission.

3. The act's failure to require that professional advocates will have a thorough understanding of severe mental and emotional illnesses needs to be remedied. Advocates must also be required to inform their clients of the possible consequences of failing to accept treatment, and they must

be held responsible for the advice they give, as are other professionals.

Bill 108, the Substitute Decisions Act:

1. The act fails to provide a clear definition of "competence."

2. The act fails to provide clear guidelines for the determination of competence.

3. The act is ambiguous on the role of advocates in the determination of competence.

Comment: These three deficiencies in the act put barriers in the way of obtaining urgently needed treatment in crisis situations. In combination they have the effect of legislating psychosis and of potentially causing serious harm to the mentally ill. Furthermore, the provisions of Bill 108 are incompatible with those of Bill 109, specifically with regard to an individual's consent to treatment, since apparently an individual's decision made when competent may be rejected in favour of a decision made by the same individual when incompetent.

Bill 109, the Consent to Treatment Act:

The act extends the procedural protections concerning a patient's rights to refuse all medical treatment in the name of protecting individual rights, in spite of evidence based on current treatment procedures and scientific research that in most cases prompt and appropriate treatment improves competency and autonomy. To fail to provide such care is to fail to recognize an individual's most basic needs.

That completes the reading of our written submission. I am not sure of the time consumed for that.

**The Chair:** That was about seven minutes.

**Mr Calder:** Is there time for each of us as individuals to make separate and individual presentations? My colleagues would like to say a few words.

**The Chair:** We are quite flexible in this committee.

**Mr Martin:** I am John Martin. I am a consumer. I am not a chronic schizophrenic. My condition would be schizoid-affective. That means most of my life my illness is more on a feeling and emotional level as opposed to a thought and thinking disorder, but I do have the potential to go schizophrenic. I did have one severe schizophrenic breakdown where for four weeks I wandered the streets hearing voices and doing all sorts of weird things until I finally walked into a strange apartment, the police were called and I was taken into the psych ward against my will. I resisted the police at first, so this was a non-voluntary treatment. But after three weeks in the hospital and with intervention, I came out of that psychosis and afterwards was very glad about that non-voluntary treatment.

I know the law does allow for the substitute decision-making act, but I think the definition of "competency" is too vague. I think I was very fortunate that after four weeks I got in trouble with the law and got prompt treatment, because research shows that the longer you are in a psychosis the harder it is to get you out of it. I got in trouble with the law after four weeks of acute psychosis and I thank God. It was providential that I did and that I got prompt intervention. I could have roamed in that psychosis for several years. If I had not got into trouble with the law I never would have gotten out of the psychosis.

The point is that if I ever go severely schizophrenic and psychotic again, I want you as a society to take me in for treatment against my will. That is the only sane, sensible and compassionate thing for you as a society to do. I emphasize that strongly. Anybody in his right mind will say that if he understands what happens to him when he is severely ill.

I had four other hospitalizations that were voluntary. I was not severely ill; I knew I needed help. It was in my acute psychotic-schizophrenic breakdown. The sicker you get, that is when you need help the most and that is when you are going to refuse help the most. That is the paradox of the right to refuse treatment. I do not want society to wait again to give me treatment against my will until I threaten to kill someone or myself or even until I get in trouble with the law. When you are severely ill you need protection against yourself, and society has to protect individuals against themselves.

I think there are signs that can be determined by a committee of a psychiatrist, a psychologist and a social worker, I would say, who can determine incompetence before you reach the point of threatening to kill somebody else or yourself, do property damage or even get in trouble with the law. That is the whole catch of how you define incompetence. Thank you.

**Mr Parsons:** There is not enough time to say the things I would like to say, so I will pick out just one or two points. I consider myself an advocate. I think I have put thousands of hours into advocacy for the mentally ill and I have every reason to. I have a son who has a mental illness.

It disturbs me very considerably that in the Advocacy Act the families do not seem to be very thoroughly acknowledged as an absolutely essential part of the care giving to the mentally ill. It also disturbs me that the professional health care workers seem to be disregarded.

I am the first to admit that there are certainly many gaps and deficiencies in the medical health system when it comes to mental illness, and I am aware from personal experience that not everybody acts very professionally or capably. That being said, though, let it also be said that the families cannot afford to do without the mental health workers and professionals. We need them and I believe they need us.

I also believe that the Advocacy Commission will need families to strongly support them. It disturbs me that in the legislation as I have seen it the Advocacy Commission is to ensure this and to provide that, but it is simply to acknowledge, encourage and enhance the families. I believe the family needs more input than that. I strongly feel that in the case of the mentally ill, the families should be taken into account a great deal more and should be represented on the commission rather than simply acknowledged.

As far as the professional care givers and the medical profession are concerned, I see that the minister may appoint advisory committees. It seems to me that this is not good enough. Please do not disregard all the advances made in medication and treatment in relation to mental health.

I just have a terrible feeling that there are some people, some consumers, who represent one extreme view regarding mental illness and are leaving out of account what I

might call the silent majority. We have one here who is not silent, but there are many. I know one person in Kitchener-Waterloo, for instance, who has been involuntarily hospitalized 18 times and he tells me he is glad he was. But I am afraid that viewpoint does not seem to come across implicit in what I understand in this legislation. Thank you.

**Mr Calder:** I think that finishes with our presentation, Mr Chairman.

**The Chair:** Thank you very much. Questions and comments, Mr Poirier.

**Mr Poirier:** I guess you realize you are not the first group that comes forward with that kind of concern. Thank goodness you do come forward and state it like it is and give the particular point of view that you have. You are quite correct, and I think the government members are very actively listening and we are also.

I do not know if you are aware that yesterday we had this young gentleman from Guelph who was describing and bouncing off his idea for him to be able to write a contract should he go off his medication or something happen where something goes wrong and he has to be brought in somewhere, picked up by the police or somebody else, and that his contract would state, "Even though I may tell you I don't want to take my medication, and even though I may sound rational or whatever, my contract says that if I am like that, something is not okay and here is the medication I would like you to give to me," and whatever.

1530

I think we were very open to consider that type of proposition to make sure that the current bills do not hinder, much less forbid, this type of thing happening, and that an advocate cannot come in there and say: "Well, the hell with your contract. You don't have to be here. You don't have to take your medication. Go home free. Collect \$200 and don't go to jail." How would you react to that?

**Mr Calder:** We are concerned about the possibility that a decision made when the individual was competent could be set aside by an advocate because the individual is incompetent and because the advocate has been instructed by a set of rules to take the opinion of the individual, the victim, when last expressed to him. I think it is good that something be done to make sure that a competent decision takes precedence over an incompetent decision.

**Mr Poirier:** Of course.

**Mr Calder:** But that does not deal with the problem as I and my colleagues in this delegation see it. There are many victims of mental illness who have no insight into their condition, are completely unaware. Although this seems to be a violation of rights, something needs to be done to see that these people get treatment.

I have a son, for instance, who has been hospitalized 15 times in the last five years, who is only now, and I am not sure, beginning to grasp the fact that he has a problem, and who is now taking tentative steps to get treatment. I do not know if he will stay in a treatment mode or not. I know another individual, a colleague of mine of almost 20 years, a brilliant historian who has over the last 10 years slowly drifted into an acute state of paranoia. She still refuses to

accept the fact of mental illness; she cannot accept the fact of her paranoia.

The result is that under the present legislation nobody can advocate for her; there is nobody who can act in any way in her support. She is going to end up on the street as a bag lady. The university has been trying for three years to provide her with a permanent pension which is provided for under our pension funds, but because she will not acknowledge illness she cannot access the possibility of that program.

**Mr Poirier:** How can somebody advocate for her, then? How can somebody legally and morally advocate for her, on her behalf?

**Mr Calder:** It is a real conundrum. I do not really know how to deal with it. I think we need some kind of review committee with the authority to make decisions in this case. As abhorrent as this sounds to the civil libertarians and the human rights defenders, I think we need some kind of judicial body that could override the will of the individual when mental illness is clearly the problem.

**Mr Parsons:** I was a high school teacher, and I am aware of a high school teacher in the same situation who has for years been disabled with mental illness, cannot recognize that he is disabled, cannot draw upon his disability pension because he will not or cannot acknowledge it. His wife has had to go out to earn her own living and has separated from him. She has found herself going around in what Dickens called the circumlocution office, going around and around and around and getting nowhere, and the man is obviously mentally ill. Incidentally, he is the son of a schizophrenic mother, but he cannot recognize his illness. I do not know. Personally I think this question of competency is just a can of worms and still is a can of worms in spite of the Weisstub commission. Let's try and put humanity, humaneness, before some of these finer points of the law.

I sat and listened to a group of legal experts primarily, lawyers mostly, in Hamilton several months ago. They talked a bit about the Weisstub findings, and they seemed to think they were not any help to them. If that is a lawyer speaking, how much help is it to the families?

**Mr J. Wilson:** I very much appreciate your comments. I have firsthand knowledge of the illness of schizophrenia in my own family and the difficulties that poses for families. I am really asking this question to head off what the government is going to tell you, all the good things that are in this legislation. You have looked at the guardianship provisions of Bill 108 and the ability of the family, for instance, to get a full guardianship over an individual who has schizophrenia. Do you have any comments on that? It seemed to me, as legal counsel for the government has presented to this committee, that this may be an improvement over the existing Mental Health Act. Have you looked into that?

**Mr Calder:** I was talking with a representative of the mental health association just the other day, and the guardianship provisions were brought to my attention as offering an opportunity or the possibility for someone like myself to take and exercise guardianship and see that my

son is provided with proper care and treatment. On the basis of this information, I think that represents a valuable contribution in the legislation.

**Mr Martin:** If I can make one comment about the Advocacy Act, I heard a doctor talking the other night about this same legislation. He said it sort of pits the advocate in an adversarial role, supposedly taking the view of the sick patient against the care giver, the psychiatrist.

I think it is unfortunate that the whole emphasis is the right to refuse treatment; it should be, when you are sick, the need for treatment. I do not want an advocate representing my views if I go severely schizophrenic or psychotic; I may want ludicrous things. I want the advocate to speak on my need for treatment and encourage me to get treatment, not to be put in an adversarial role.

We are setting up here another crazy adversarial situation in society, the advocate against the psychiatrist instead of both working together; the right to advocate for the rights of the vulnerable, to be protected against yourself, to get treatment when you need treatment and early intervention. I said previously that the record shows that early intervention empowers people, but first you have to bring someone out of an acute psychosis before an empowerment process can begin. I think advocacy is not just the rights of the patient; the needs of the patient should take priority even over the rights of the patient. When you are severely ill, your needs take priority. I know that from experience. Your need for treatment takes priority over your rights, what you may say.

**Mr Parsons:** I would like to recommend that the members of the committee read the article in the Canadian Medical Association Journal in October called *The Right to Remain Psychotic*, in which two mentally ill people were kept without proper treatment for five and one half months in one case, seven months in another, because they went through all the review and appeal processes.

I put it to you that there is nothing as far as I know, as far as I can see, in this legislation to speed up the legal processes, and there needs to be. I do not believe that somebody who is allowed to be psychotic for five and a half or seven months is getting the proper treatment; we would not allow it to happen to a dog.

**Mr J. Wilson:** Provide that to the clerk, sir.

1540

**Mr Parsons:** I draw it to your attention. It happens to be two psychiatrists from Queen's University and they are talking about a facility within the prison system. They make the point that similar things are happening elsewhere, outside the prison system; some of us know that they are. Nothing in this legislation, as far as I know, guarantees that those incompetent, psychotic people are going to have the legal processes dealt with promptly. That needs to be attended to.

**Mr Calder:** I want to comment on the question of guardianship. That is potentially a good long-term solution, it seems to me as a parent, but it too is slow to implement. What we have needed as a family is instant help, and instant help has not been available. As a family we have stood by for eight and 10 weeks while we have watched

our son slip into an acute psychotic phase. In that phase he is extremely paranoid. He is extremely hyper, wandering about day and night, unable to eat, unable to function. He gets increasingly incapable of functioning. He can start off providing himself with meals, and he is quite good in those kinds of tasks. He is, incidentally, an extremely bright man of exceptional ability. In the run-up to these psychotic phases he can still solve complicated mathematical questions, but he cannot make sound decisions about daily care and he becomes increasingly incompetent.

We have not been able to get him help until he crosses over the line, until he is threatening to injure somebody else or is threatening to injure himself directly, either committing suicide, walking up the 401 or wandering off into the night when the temperature is 22 degrees or 30 degrees below freezing. This has happened. What I think we need as parents is some kind of provision that can make for immediate care in times of crisis. He certainly does not recognize his own critical state during these phases and certainly denies up to the very last that he needs hospitalization, that he needs help. In the meantime, the family is drifting day by day into greater danger.

I am 62. I feel I am a very well man, but in his last crisis he and I ended up fighting in the hallway over a deliberate provocation. It is all right, I won the tussle. We called in the police and he in fact ended up—well, that is another story. But you see the kind of situation that can develop. He ended up assaulting a police officer and was taken into custody, charged with assault.

**Mr J. Wilson:** Just to let you know where I am coming from, I understand that situation exactly, as you describe it.

**Mr Calder:** We need assistance in times of crisis, and under the present legislation we cannot get it. The advocates always standing in the way of getting long-term, effective treatment do not assist the achievement of that goal.

**Mr J. Wilson:** I have made it clear in this committee that my thoughts would side with you. We have had a lot of testimony, though, that would tell us that, no, advocates do not do that and will not do that. It is a tough one. I have also spoken at length about—I am in opposition so it is easy for me to say, but I expect the government's hands are somewhat tied by the Charter of Rights in this legislation also. I would never have voted for it. I do not belong to the party that voted for it. It is that the individual is supreme. Even if we were to concoct some model whereby we could have significant input from the families in terms of emergency treatment I am not even sure it would stand up in today's court. We are in quite a bind, I think.

**Mr Parsons:** Same thing as a "notwithstanding" clause.

**Mr J. Wilson:** That is true. Premiers cannot seem to agree on anything these days.

**Mr Wessinger:** Thank you for your presentation. I can certainly understand your frustration in dealing with the problem of the schizophrenic situation and treatment. I know how frustrating it is. However, I think some of the statements made in your brief are not quite accurate. You state that an individual decision made when competent may be rejected in favour of a decision made by the same

individual when incompetent. That is not true, because under the new Consent to Treatment Act it is clear that if a person makes a power of attorney for personal care, and he is incapable, the treatment as set out in the attorney for personal care is to be followed.

It is also clear in law that if a person is incapable, then the substitute decision-maker does make the decisions. It is not true under law, either existing law or proposed law, that an incapable person's decision overrides a decision made when he was capable.

**Mr Parsons:** We put the word "apparently" in, if you look, because we were not sure; we are not lawyers. That is why we put the word "apparently" in, because it was written in such a way that we were not quite sure.

**Mr Wessinger:** I can assure you that it is. I agree with the frustrations in the area of determining capacity. I agree that is a difficult area. If we go to the other comment, saying the act extends the procedural protections, I would suggest to you that the act contains nothing that is not already existing in the Mental Health Act. We are advised by our counsel that in fact under this act it is easier to admit patients to hospitals than it is under existing law.

We asked for some of the transcripts to be made available of previous discussions in this regard. I would ask that they be made available to you.

**Mr Parsons:** May I respond to that? Under the existing law, theoretically we should be able to get people into hospital when they are incompetent and a risk to themselves or others. In practice it does not work like that. I was looking today at some figures showing that in our local hospital a few years ago, out of 870 admissions in that hospital in the course of a year, two were involuntary. This is way out of line, incidentally, with the rest of the province.

Why is that? I can assure you from bitter personal experience there is more than one in 400 or so who needs to be admitted involuntarily. I can assure you. Why is it? Part of the reason is because of the legal hassles the psychiatrist would rather not face. That is one reason. Another reason is that not one general hospital in the province, according to Dr Heseltine who wrote a report a few years ago, has a secure facility to handle—not one of them. We are not talking about the 10 provincial psychiatric hospitals, just the general hospitals. In other words, they apparently have not got the security they need to handle some of these people, so their families are left—

I know of a gentleman 84 years old with a son almost 50 who is very disturbed. The old lady, his mother, has had a stroke. They live in an apartment. He was taken to court before Christmas because he was threatening tenants, this fellow. He was admitted, yes, and they held him for seven days and they turned him loose again. That fellow has an axe in his apartment and is a time bomb waiting to explode. That is a situation we face, and many of us face. Then the victim of a negligent mental health system will be blamed.

The gentleman who is believed to have killed that young lady in Burlington was 30 days in the Clarke Institute. He asked to be retained, kept there, this Mr Yeo. They turned him out and two people, three people counting the

man himself, died. That is our mental health system. It is not acceptable to the families who have to deal with it. We are not equipped to run psychiatric boards. My wife is going to be 73 shortly. I am not equipped and she is not equipped to be on duty 24 hours a day.

This question of competency is a very real thing to the families. We ask you to consider the families a lot more. We are the front line. We are the care givers. The professionals say they are in the front line. Not so. It is the families. We want the best for our relatives.

1550

**Mr Winninger:** Thank you again for your presentation. Having served on the local board in London of the Canadian Mental Health Association, I know the important role you play. I am not unsympathetic to your concerns in a general way. I know my colleagues want to speak as well, so I am going to be very brief and just address your points in regard to Bill 108. You suggest there is not a clear definition of competence and the act fails to provide clear guidelines for the determination of competence.

If you can find a better way of expressing incapacity than we have done in section 46 I invite you to submit a more detailed proposal for that, but certainly the test for incapacity for personal care is set out in section 46. It is referenced in section 50 when we are dealing with validation of powers of attorney for personal care. It is referenced again in section 55 when we are dealing with court-imposed guardianship.

As to what Mr Wilson alluded to in regard to the kind of remedy Bills 108 and 109 provide in the kind of situation you described, where the patient at the time treatment is offered may, because he or she is delusional, refuse treatment the patient may later have wished to have taken at the time, the court guardianship that can be ordered under Bill 108 places the care giver in a position to consent to treatment, as you know, on the patient's behalf, to consent to admission to a psychiatric facility, and it is all deemed to be voluntary rather than involuntary.

Your concern was that it takes a lot of time. That is why section 59 is in the act. For urgent cases you can apply for temporary guardianship to achieve that very same purpose. There may be better ways of expressing the legislative intent. If you have some precise suggestions, let me know, but I think broadly the mechanism is there not only to serve the best interests of the patient but at the same time to safeguard that patient's integrity and right to self-determination.

**Mr Parsons:** There is no reference, as far as I know, to what we all know of if we live with the illness, an ongoing process of deterioration. That should be taken into account. Competency: I defy anybody—King Solomon himself could not really be clear. I have asked one of the best psychiatrists in Ontario how much of my son's actions is he responsible for and how much is he not. He did not know. The best psychiatrists I have come across are the ones who say, "I don't know." Nobody in this room or anywhere in this province can really define competency accurately.

What is not taken into account is this process of deterioration. The care givers, my wife for example, could tell you when my son is in need of care. Thank goodness he is at the stage now where he knows it himself and he goes and gets care. He is lucky, because some of the ones I know who need care, they know it, they go to the—and they are turned away. They get it both ways. They cannot get in because of the restrictions of the mental health legislation. When they go voluntarily, they are turned away. It is a catch-22 coming and going. The families are the ones who are taking the impact. This province is going to have any number of dreadful situations on its hands as people get older. We cannot indefinitely carry what we are expected to carry.

**Ms Carter:** I have to say that it seems to me you have misunderstood in a very profound way the intent of Bill 74. The whole point and thrust of that bill is that the advocate will go to the vulnerable persons themselves, the consumers, and will find out what their wants and wishes are. The advocate does not make any judgement. They act on those wishes. By definition, this has to be somebody who is competent enough to know and express his own wishes. So I suggest that somebody in an acute psychotic phase would not be involved in this. Also, I think your request that professionals and parents be on the commission is again a misunderstanding, because they are not consumers in any sense of this.

Having said that, obviously family and professionals are of vital importance in the lives of most vulnerable people and have a great deal to offer them. But there are exceptions. There are times when they can be part of the problem, and those are the cases the Advocacy Act is particularly targeting. There are people whose family problem may be part of why they are having mental problems. I am not saying in most or even many cases, but we have heard a great many submissions on this committee. We have heard very many points of view.

We had a young man yesterday who had found a medicine that suited him—he was a schizophrenic—and he said, "Please, can my wishes to have this medicine forced upon me when I say I don't want it be respected?" I would see an advocate as going along with that.

Contrarily, there are people whose experience with medication and treatment have been so horrendous, certainly from their own subjective point of view, that they also have a right to say they would not want it.

I have a question for you. You say advocates must be required to advise of the consequence of failing to take the treatment. First, is that not the doctor's job to say to them what the treatment is going to do to benefit that person? And what about the doctor's job also of explaining what the side-effects and the not-so-pleasant consequences of taking that medication or undergoing that treatment might be as well?

**Mr Parsons:** How do you know a doctor is going to be involved?

**Ms Carter:** If medication and treatment are being prescribed, obviously.

**Mr Parsons:** The doctor has probably already told the patient, "If you don't take this, such and such will happen."

The patient, because he is delusional, because he is irrational, because he is out of his mind, because he lacks insight—

**Ms Carter:** But I am saying this should hopefully be done when the person is in a lucid state.

**Mr Parsons:** But you see, your problem, madam, is that you, like me I think, have never been out of your mind. It is unbelievable if you are a rational person. You are logical; you would not be sitting there otherwise. It is the most difficult thing in the world to put yourself in the place of some—

**Ms Carter:** Could I just butt in there and tell you I had a sister who killed herself with her medication.

**Mr Parsons:** Yes, but that does not mean you have been able to put yourself in the place of somebody who is out of her mind. I find it extremely difficult, even after 20 years or so, to understand the way my son's mind works. You cannot explain things to somebody who is completely irrational as if he were rational.

**Mr Calder:** We think an adversarial situation is being set up here in which an advocate is going to take the side of the patient who is, as we emphasized right at the beginning of our presentation, not of sound mind and judgement, over the assessment of a health giver, a psychiatrist, a parent, who can see the deterioration in the situation of the victim etc. The advocate seems to be required by the legislation to act in the interests of the victim as expressed by the victim. We think the advocate, in these circumstances, should be well trained in the effects and characteristics of, and he or she should have a good understanding of the effects of the illness when he or she is advocating on behalf of that individual and so should advise the individual of the consequences of refusing treatment. That is why we have put it into our brief. That reinforces what the doctor is saying, of course, but it is probably in the best interests of the victim.

1600

**Ms Carter:** But you have also said that it is very difficult to define the point at which a person ceases to be competent, so I think we have to be very sensitive to both sides of that line, that sometimes a person may be expressing a wish that is not entirely sane to refuse treatment or whatever, but then we could err on the other side and force treatment on somebody who has a rational subjective reason and desire not to undergo it.

**Mr Calder:** I know that treatment is difficult nowadays. This is not a properly understood subject, as we indicate. Treatments are not going to be regularly effective, but in my experience, it is not good to have a psychotic individual like this wandering around on the streets, not taken into any kind of protective custody whatever.

**Ms Carter:** I do not think anybody is suggesting anything like that.

**Mr Calder:** I guess one of the reasons why we are here is that the present terms of the Mental Health Act represent a serious barrier to treatment or to satisfying in any way the needs of a sick individual. The court system seems to be hesitant to act.

If I might exemplify it with the case of my own son, this summer he assaulted a police officer. He was arrested; he was taken into protective custody. The court did not want to deal with the real problem, which was a mental health problem. We thought it would probably recommend a treatment of some kind, or at least examination. What the court did was throw the case out. Our son then was on the street within two or three hours. He broke into our house. He represented a threat to the other members of the family. The police were called in again. He had a baseball bat to protect himself, so a SWAT team was brought in to take him into custody. Even at that point the local hospital was not sure whether he should be hospitalized or not.

What we are concerned about is the difficulty of getting treatment even under the present legislation, and this is where we come to the advocacy part you criticized at the beginning. We think that when the terms of reference of the advocates are set up, they must take into account the counsel of parents and of care givers who have been involved in these kinds of crisis situations for years now.

**Mr Martin:** Can I just make one comment? I do not claim to understand all the technicalities of this legislation; I will admit that. All I think is that it is too difficult to get severely mentally and emotionally ill people for non-voluntary treatment. You pretty well have to be either threatening to kill yourself or someone else or get in overt trouble with the law, and I think there are clear signs of incompetence before you reach that point. As I said, I want you as a society to take me for treatment against my will before I threaten to kill myself or—I will repeat it again—somebody else or necessarily get in trouble with the law. Next time I may not be as fortunate to get in trouble with the law in four weeks. I may go psychotic for several years and never come out of it. That is not advocating for vulnerable people.

**Mr Malkowski:** Thank you for your presentation. I think it is important information and beneficial for the members to hear.

One thing I would like to tell you from my own personal experience is that I had a best friend as we were growing up who was deaf and he became schizophrenic and he needed to go for treatment, so he was helped along in his process.

I have already worked at a group home for people who were deaf as well as schizophrenic. I have had that experience and I have seen that treatment does help the people to become stabilized. I have had training and I have had some very difficult experiences in that situation.

There is another story I would like to share with you about my friend who was schizophrenic. He was misdiagnosed as a schizophrenic and a psychiatrist forced him in for treatment. The problem was communication. Some situations are similar to this, where the patient is not schizophrenic but he is stuck because he is labelled incompetent.

Last week we heard from psychiatric survivors who shared their experiences of misdiagnosis as well. Not all of them, but some of them said this was a problem. My question to you is, how do we become accountable for supporting that group of people who really do not require treatment

and have been misdiagnosed and have gone through that experience? Perhaps they are acting the way they are because of sexual abuse or other problems.

**Mr Calder:** I know it is a very difficult problem. It would test Solomon. It would test 100 Solomons, probably, but alongside of these people who have been mistreated by the system, there are those who are mistreated in a different way because nothing can be done to help them. They are forced out on to the street and die there, I guess, under the present legislation, as you have probably heard many times now, dressed in their rights.

I know clearly only of the experience of parents like ourselves who have a seriously ill child or sibling who cannot function as an independent individual in society in spite of being gifted in many ways and who might benefit, who probably would benefit, we feel now, from the kinds of treatments available. Advocates can speak for those people, just as we parental advocates speak for those people, to see that they are not abused by some malfunction of the system, a serious mistake by a psychiatrist about medications. I know these medications are kind of lethal weapons, or can be lethal weapons, but they seem to offer some hope for the treatment of people caught in a hopeless situation.

You know there are some, a third, who have one instance of psychosis. You know there is another third who function pretty well with present treatment regimes involving medication, psychotherapy and psychosocial treatments, but you probably know too there is another third—and I think now, tragically, our son falls into this category—who cannot be helped with medication, who cannot be helped with any of these things and whose life expectancy is limited—bleak, at best—because they are either going to end up on the street or they are going to end up in confrontation leading to violence with the police or some other type of authorities. It is a very difficult situation. You have to treat all, I think.

**Mr Malkowski:** Can I ask briefly whether you would be willing to agree that the advocates would be able to respect the vulnerable person's wishes to continue treatment if he wished to do so, for example, if it was a schizophrenic person who wanted to continue treatment, and at the same time respect that other people need protection from being forced into treatment because they have been misdiagnosed. They could fulfil both functions?

**Mr Calder:** Okay, yes.

1610

**Mr Parsons:** I would like to say that I think the Advocacy Act is probably admirable for many groups, because that act is not designed just for mental health. In Kitchener, on Monday of this week, we heard a Ministry of Health official say that the Ministry of Health does not consider that the Advocacy Act is a part of mental health legislation. Right? She said that very clearly. It will impact, nevertheless, on the mentally ill.

There certainly are cases of abuse among the mentally ill. My own son was almost killed with lithium treatment. He was not listened to by the doctor. My wife was not listened to by the doctor. It ended up with his having some-

thing called a thyroid storm that put him in intensive care. He looked like an Ethiopian famine victim. He has been permanently damaged with the medication, and that is just a tragedy we have had to live with.

Nevertheless, I know enough to know that most of these people need some medication. It needs to be monitored much more carefully, and yes, I believe there are cases where an advocate may be needed.

The family is usually the advocate, and we feel we are being pushed aside. We know our family better than anybody else, and in too many cases, families are pushed on the sidelines. Please allow a place, an input for the care givers. We are the primary care givers.

The Graham committee had the right idea. I see dangers in this legislation. The focus of Mr O'Sullivan and of Mr Graham in his report was on the consumer and the family both, and the families here are being pushed on the fringes, which may be in order for some of the other conditions the Advocacy Act is meant for, but I do not believe it is appropriate for many of the mentally ill.

**Mr Martin:** May I just make one point? If I am correct, if the advocates are not there to advocate for the incompetent, then we are straying totally away from the Graham commission. They are the ones who most need advocacy in the true sense for their needs.

I feel a loner, like many consumers. We have consumers speaking about the need for self-determination, the need for empowerment. That all applies when you are out of the severe stage and on the road to recovery. Like a child growing up, the older it becomes, it can have more self-determination. If you have mentally regressed, does a six-year-old have the right not to go to school? If you were psychologically mentally regressed to the level of a child, then the advocacy defeats its purpose.

When I become severely ill, when I become incompetent, then that is not even the role of the advocate. I agree I misunderstood that. If the advocacy is not there for the incompetent person—they are the ones who need advocacy the most to encourage, and even the place for non-voluntary treatment, the need for treatment. Then we need to have a different view of the advocate.

**The Chair:** Thank you very much. We have to move on now.

**Mr Poirier:** Mr Chair, two seconds. I want to thank you for taking the time to come forward. Unlike another member of this committee, I do not feel like accusing you of not understanding the act. It is not a question of understanding or not.

**The Chair:** Thank you, Mr Poirier. Professor Calder, Mr Martin and Mr Parsons, on behalf of this committee I would like to thank you for taking the time out to give us this presentation.

**Mr Calder:** Thank you for giving us the time.

MARGOT HAMBLÉN

**The Chair:** I would like to call forward our final presenter for the day, Margot Hamblén. Good afternoon. Please be seated. As you know, you will be given half an hour for your presentation, but the committee would appreciate it if

you would keep your remarks to about 15 minutes and allow time for questions and responses. Could you please identify yourself for the record and then proceed as soon as you are comfortable.

**Ms Hamblen:** Yes. My name is Margot Hamblen. I am president of the Leeds and Grenville chapter of the Ontario Friends of Schizophrenics. I am here today to tell a bit about our own personal family problems and what we have experienced, and having listened to the portion I have been in this room for in the last half-hour, the story sounds very familiar. I am hearing it over and over and over again.

As the mother of a young man who suffers from a double whammy, that is, schizophrenia and addiction problems, I am pleased to have this opportunity to express my gravest fears about the current legislation of Bills 74, 108, 109 and 110. I know I am speaking for many other families as well because I often meet people with similar problems. I also read about it time after time in our local newspaper in the court cases column. I also know that a large number of prisoners in our penal system suffer from schizophrenia, many of them with the added problem of addiction.

Here is a condensed story of some of the hell our family has lived through. I hope it will point out the need for access to help for severely mentally disturbed people, usually schizophrenics, who are usually unable to recognize that need for themselves.

David first became psychotic in June 1981 at the age of 19. At the time, we attributed it to the effects of drug and alcohol abuse after having sustained a head injury two years previously. I might add, however, that for a year following his accident and rehabilitation he functioned and behaved without any serious problems.

He was admitted to Kingston General Hospital and was being treated for severe psychosis, but he ran away several times so he was transferred to the Kingston Psychiatric Hospital. However, the doctor at KPH discharged him a day later, saying that he could not certify him because of the Mental Health Act. The next seven weeks proved to be a living hell for the whole family, with his delusions, his tantrums, his fears that people were out to attack him, to rape him and trying to poison him.

Finally, after these seven weeks we got him admitted to the local general hospital for an assessment. However, on day four he ran away. We found him on the outskirts of the city of Belleville. He was transported by the police to the KPH, where he stayed approximately two months. Then, for the subsequent year or so, he lived in various places until he would be asked to leave because of his bizarre behaviour and/or his substance abuse.

At least twice he somehow managed to get down to Los Angeles, convinced he could make himself famous and rich with his guitar. After a few months there he would be flown back to Canada by LA county because he was in trouble with the law. He needed psychiatric care and he was not eligible for it down there. He had been in a state mental hospital there for a couple of weeks, I believe, for assessment on one or two occasions. At the time had also been prescribed medication.

I remember all too well one of the times he was flown back to Canada. I met him at Toronto airport after first arranging for a bed at KPH and an appointment with his doctor there. We were living in Belleville at the time. David said he did not want to go to KPH, he did not want the hospital, he did not need anything and there was nothing wrong with him. He started to get hyper before we got halfway there. As we got closer to Belleville on the 401, he attempted to jump out of the car. I really had no choice but to go right on into Belleville and let him out.

However, he found out there were no friends willing to accommodate him in his state, so he came to us the next day to get his ride to KPH. He stayed a couple of months. That doctor did certify him, but when discharged David did not want to stay in a group home. He wanted to be on his own. There was "nothing wrong" with him. In the past 10 years, David has never been able to handle himself and manage things on his own. With his problems it just becomes a disaster. It was not long before he was arrested again.

Once again we have a combination of his delusional behaviour, discontinuation of his medication, and alcohol use, which led to problems and charges that could only become more severe as the years passed. It reached a point where nearly every member of the police force knew my son. They recognized that he was sick and that he needed psychiatric help and they were sympathetic to our frustrations. If I had a dollar for every time a doctor or policeman has told me his or her hands are tied by the Mental Health Act I would have a nice, healthy nest-egg right now.

Because of our son's unwillingness to accept psychiatric treatment, he invariably ended up being arrested, charged, ordered for an assessment at KPH—usually 30 days—returned to court and then sentenced to the detention centre. This is the pattern which has occurred on average every 10 to 18 months. If the incident is not a major one, the KPH assessment is often left out.

Even when my husband and I could see some deterioration in David's mental state, as parents we did not seem to have an avenue to follow to get prompt treatment for him. I reached the point where I could usually predict with some accuracy when a crisis was imminent. David was not living with us at home at the time and I want to explain that right now.

1620

Unfortunately, instead of getting the psychiatric help he really needed he was being assessed and spending time in detention centres. I have lost count of the number of times this pattern has occurred, but I should mention that it has been frequently enough that the past nine or probably 10 years, now that we are in 1992, have all been spent in and out of psychiatric hospital for assessment and in and out of detention centres, all on probation.

For about two months prior to January 1989, we saw David getting more delusional again. We suspected he had gone off medication and was probably drinking again. I predicted the lid was about to flip. I wrote a note to David's local GP and I wrote a note to his lawyer and his probation officer saying: "Look out. Something is going to happen."

He would phone us with his delusional fears that people were coming to attack him or that some man or some woman had some men set up hiding in the backyard of where he was living and that he was waiting for them to attack him and so on. It was about 20 minutes after one of these calls to us, during which we tried to reassure him and calm him, that he was arrested for threatening his neighbour with a pitchfork. We do not know anything about this. I talked to him 20 minutes before, remember. Please try to imagine what it is like to pick up your local newspaper the next day and see on page 1: "Neighbour Threatened With a Pitchfork." There was no mention that this was a sick boy because the media people did not know that he suffers from schizophrenia.

Here we go again with the usual routine that I outlined a little while back. We never did get an explanation as to why he did not meet the criteria of the Mental Health Act to be certifiable. I remember writing to the Minister of Health at that time and asking if our system waits until the pitchfork pierces the heart before we can consider certifying him as involuntary.

Our interpretation of the Mental Health Act, incidentally, concurred with that of the crown attorney and David's lawyer. We all found the doctor's decision unbelievable when it was read aloud in the court hearing. I remember even the judge shaking his head in disbelief when the diagnosis, "chronic delusional-type paranoid schizophrenia," and the statement that he was not certifiable under the Mental Health Act were read in court. The judge wondered aloud why the mental health system kept shifting David back into the court system.

Perhaps the most positive thing to come out of that sentence, if anything can be positive about a very sick person being treated as a criminal case, was that David did apply for and transferred to the treatment facility at the Rideau Correctional and Treatment Centre in Burritts' Rapids. Here he had understanding and helpful counsellors and was seen regularly by a psychiatrist from the Royal Ottawa Hospital, whom he grew to respect. He even served a few weeks of his time in that hospital when they were afraid that he was getting a little too hyper and might not be able to be handled by the staff at the facility. This doctor has continued to see him in Ottawa, where David has been for nearly a year. His probation officer there is a caring and helpful person who deals mostly with ex-psychiatric cases.

However, to me all this makes a very sad statement about our system and society and the way some severely mentally ill people are looked after. This is how so many of our schizophrenics are allowed to slip through the cracks, most of them often ending up at the bottom of the crevasse. If you have never witnessed someone in a schizophrenic crisis it is difficult to find the words to accurately describe the impact it makes on the whole family, especially when we do not know what to do because our hands are tied.

I have just touched on a few incidents in our own 10-year history, but I would like to go back to that first horrendous summer of 1981, to those seven weeks when we did not know what to do or where to turn to get prompt

treatment. I want you to try to imagine trying to calm someone who is ranting about being poisoned. He is screaming obscenities at his family and even yelling and roaring that his mother is a prostitute. I can chuckle about it now. People who know me get a chuckle out of that.

Anyway, when we finally persuaded him to go down to emergency and see somebody, while he was waiting to see the doctor he was getting more and more hyper again. My husband, who was with him at the time, not myself, was trying to keep him calm, saying: "Keep down. We're going to see somebody." He was held down and he was going to go out and leave. Try to imagine what it is like: You have this family member whom first of all you want desperately to be calmed down to be able to be helped, ladies and gentlemen, and you are told you could be charged for holding him there against his will.

Logic tells me that David's right to refuse treatment while he is in a crisis gives him the right to raise hell and gives him the right to abuse people and/or property until the police are called and arrest him. Should he not have the right to necessary help in order for him to function better in the community?

Logic also tells me that all the recurring costs of his legal aid, court costs, incarcerations and hospital stays multiplied by the hundreds of others in similar circumstances have to be phenomenal. We know that if these schizophrenics were pulled from the cracks and treated for whatever time it might take to enable them to function with some support, at least one third likely would not need hospitalization again. Many others likely would not be incurring a lot of costs to our judicial system and many others might get along much better in society with perhaps only occasional setbacks. Is this not worth a try?

One of the saddest cases I know is that of a young man from Belleville who had suffered with schizophrenia as well as some substance abuse problems and who was in and out of hospital. He too would not stay voluntarily. He ended up heading out west thinking he could get a job, and then things got bad. There was no work. He was not employable and ended up homeless and drifting until finally his family did not hear from him. The RCMP had no word. The Salvation Army had checked across the country and said that no, he had not shown up at any of their hostels, and 11 months after their last contact the father called me and said: "Margot, I want you to know I've just had a call from the RCMP. They've found David's partially decomposed body just outside Prince George."

I have to presume that these bills, while undoubtedly a boon for many vulnerable people not afflicted with brain disorders, were drafted by people who have no real firsthand knowledge of or long-term contact with severe schizophrenia and other severe brain disorders. They must not realize that the very nature of schizophrenia prevents the sufferers from realizing that they are sick and in dire need of help.

I do believe in rights, whether it is the right to drive a car or the right to have a baby, but with rights go responsibility. Ladies and gentlemen, you and I know that if we are not responsible to these rights we are granted, we lose those rights or we can lose those rights. Do schizophrenics

not have the right to be helped to be responsible citizens rather than chronic court cases?

1630

My husband and I have often wondered what it would have been like had David been given long-term treatment for whatever length of time was needed 10 years ago, followed by proper after-care support and programs. We are still wondering, and we are also wondering how many more times this cycle is going to be repeated and if we will ever see the light at the end of the tunnel.

We believe a terrible injustice has happened to schizophrenics, their families, the community and the taxpayers of Ontario. I presume many of the MPPs know someone with schizophrenia or a relative who has someone in the family with schizophrenia. I am sure those members will thus be familiar with the agony that is suffered by both the family and the victim of the illness. If this is the case, I hope you will know why we are so anxious that access to prompt help be more available than it has been heretofore.

I have added three pages with some news clippings. This sort of thing appears in the Brockville paper quite frequently. These are some examples of what can happen. On the first page of those I made a note. I left out a very important word, but I handwrote it at the top. I left out the word "untreated" in front of "schizophrenics." I hope everybody will insert that, because it is most important.

**Mr Poirier:** I am going through those clippings. It is very bizarre that in 1992 people who are ill can end up being treated like that. I am sure the media enjoy the pleasure of heading things like, "Court Regular Sentenced for Breaking into House." If you go by the headline alone, you would say, "What a hell of a criminal we have here." I feel for you and I feel for the point you are bringing forward. I think it is extremely important that you come and tell us that, hopefully so that the government members will influence the government to make sure that when you need quick care like that, it is more important to get the care now. Then you would not have all of this. The reporters may have a heck of a lot fewer incidents to report out of the courtroom if people got the proper care they deserve, need and want.

**Mrs Hamblen:** At the time; it is very important.

**Mr Poirier:** At the right time and place. It is just incredible to see that. I will never again look at articles like that without checking for the words "psychiatric" or "schizophrenic." I will understand better and see a lot more clearly.

**Mrs Hamblen:** Letters to the editor in the local newspaper as well appear periodically, and some of them are from people I know who have schizophrenic relatives. If I may quote from one—I am not going to read the whole letter—she was responding to an article in the paper. She did not like the way the paper handled certain aspects of it. She says:

"The courts place this man in an unlocked ward where he can walk away at will, and tell him he must seek treatment. Does the court believe after listening to his testimony that a mentally incapacitated man can make a rational decision? Who is insane here, the man or the sys-

tem? Of course he does not comply, and as a result of this the police officers are expected to do the job the Ministry of Health should be doing."

She ends by saying: "We have one of the finest health care systems in place"—she is referring to Brockville—"a psychiatric hospital with a well-trained staff to take care of people, but something is missing: a law to enable these people to do their job properly. The patient should not be the victim."

**Mr Poirier:** I tend to agree with you. I think the system is a hell of a lot sicker; just this point here, "The crown concurred that Peer should be in the hospital, but acknowledged 'that's not possible.'" I think the system is screwed up.

**Mrs Hamblen:** I do not have any legalese or expertise, but in one of the court systems I learned that a judge cannot sentence somebody to a hospital for treatment.

**Mr Poirier:** Most interesting. In spite of four and a half tons of evidence, right?

**Mrs Hamblen:** Exactly.

**Mr Kwinter:** My heart really goes out to you after looking at the history you have suffered with your son. One of the major problems is one of education of the general public and the courts. I think most people reading the article you have submitted that appeared in the Brockville Recorder and Times, particularly the sentence that says, "He is diagnosed as a schizophrenic with an anti-social personality enhanced by drug and alcohol abuse," would consider that a criminal as opposed to a health designation. That is one of the problems we have, that people would look at it with that headline and say, "Oh, this guy has a problem, not a health problem but an anti-social behaviour where he has to be put away." I think it is an education problem as well, and I commend you and your organization for trying to bring this to the attention of the general public and legislators so they can be aware of the problem.

**Mrs Hamblen:** You are very correct, I think, about general public education and public awareness of illnesses such as schizophrenia. There is still a lot of misconceptions out there, as you know.

**Mrs Cunningham:** Thank you, Mrs Hamblen, for a most emotional presentation. You are quite right: I think most of us in the room who represent the public do know schizophrenics. We have them in our families. As well, I am the mother of a head-injured son who has a lot of the symptoms you have described.

What I have had to say to my constituents as they have come to my office in regard to this legislation is that the concern you have expressed today will not be taken care of with this legislation. Anybody who pretends it will is not correct; that is the way it goes.

However, there are improvements on behalf of advocates in the legislation. We are trying to listen to the public—I think all three parties are trying to be as non-partisan as they can—in order to correct it as far as possible.

With your indulgence, I would like to ask a question through the Chair. It concerns me when we sometimes leave some of the people who come before the committee with no hope for change. I do not know how we do it in

our committee system, Mr Chairman. I know, Mike, that you care as much as the rest of us. In this instance, it is my understanding that there would have to be changes to the Mental Health Act. I would like some verification of that—not only for Mrs Hamblen; the previous witnesses probably should have been advised. I am wondering if we can hear from counsel on that to see if I am correct.

**Mr Wessinger:** Actually, I would like to respond, because I was going to ask a question of the witness that I thought might clarify some of the problems. I think there is a lack of education with respect to the problems of schizophrenia, not only in the general public but also in the health care profession, particularly among physicians. If I could ask the witness a question, it might clarify.

**Mrs Cunningham:** That will be just fine if we are both on the same tack; whatever is most appropriate.

**Mr Wessinger:** As you know, under the Mental Health Act now, people who are dangerous to themselves or others are supposed to be admitted to hospital. Time upon time, I hear examples of people who to me clearly appear to be a danger to themselves or others who are taken to the hospital and refused entry. What I am suggesting is, does it not appear that the physicians are not using their judgement in admitting people who ought to be admitted presently under the Mental Health Act?

**Mrs Hamblen:** I often got the feeling that doctors—well, some of them used to admit back in the earlier stages 10 or 11 years ago. At KPH I was often given to understand, “Oh, our hands are tied because of the Mental Health Act.” I remember in one instance calling the Ministry of Health. I talked to a legal counsel there and he said, “No, there shouldn’t be a problem, from the sound of things.” I said, “Are you trying to tell me that the doctors have more power than they are using?” He said, “In many cases yes, especially in the provincial psychiatric hospitals.”

**Mr Wessinger:** I think that is almost what we call a systemic problem.

**Mrs Hamblen:** But on the other hand, I am still asking, what is going on here? Is there nothing that is black and white? If a person is a danger to himself or an imminent threat—

**Mr Wessinger:** It does not even have to be imminent, by the way. There is no requirement that it be imminent. The legal test is purely danger, and there is no requirement that it be an imminent danger.

1640

**Mrs Hamblen:** I sometimes wonder if doctors are saying it has to be an immediate threat. Perhaps this is the way some of the doctors—I do not know. There certainly is that reluctance to accept and say, “Let’s give this a try.” That is why the one doctor did go out on a limb. I talked to him and said: “Doctor, you and I know that perhaps he is not dangerous to himself at this point. He’s not suicidal. He can get violent and vicious. Isn’t there something about not being able to look after himself? You and I know what he’s like. He can’t look after himself, feed himself—it’s almost animal-like.” He hemmed and hawed, but he said, “I’m going to certify him for 60 days.”

That was the only doctor in KPH at that time who I felt was saying, “I’m going out on a limb, but I don’t think we really have anything to worry about.” I was not worried about it, because I knew I had enough if anybody were to take this up with a review case or a review court or anything. I was not that worried; I would cross that bridge when I came to it. I do not know what the thinking is, generally speaking.

**Mr Wessinger:** Under the act, there are some provisions that will make it easier.

**Mrs Hamblen:** As you can see, it has obviously not been working, not just for me, but for many other people. This act has not been working for years. I am also very frightened about the legislation now. I see it as becoming more and more difficult to access whatever help is needed when it is needed, by having to go through an advocacy system and a guardian system and a substitute decision-maker. What is the matter with me? I know this boy better than anybody else does. What education has an advocate who is called in to talk to him and tell him what his rights are, that he has the right to refuse this? How much about his actual case and behaviour would that advocate know? This is of grave concern to me.

**Mr Wessinger:** I might add for clarification of what you are saying that this act does not create any more rights with respect to your son being committed under the Mental Health Act. The same rights will prevail, but there are some additional provisions which we hope will be of some benefit. These provisions are set out in section 19 of the Consent to Treatment Act. For the first time, a substitute decision-maker is given authority to consent to a treatment and to consent to admission to a hospital. You being the mother of your son, you would be the substitute decision-maker in that instance, because you are on the list—

**Mrs Hamblen:** Excuse me, would his parents be the first ones to be called upon, or do I understand that he would have the right to choose his best buddy, Joe Blow who lives next door, to say, “I want you to go to bat for me”?

**Mr Wessinger:** If he is determined to be capable, he would have the right to determine someone else, yes, but he would have to be capable to make that selection of someone else; although, if the question of guardianship came up, his wishes could be represented if he wanted to dispute you being given that authority in a guardianship application. That is the other aspect. I will leave it to one of my colleagues to deal with the guardianship aspect, because we think that is another area that could be of great assistance in this regard. I think we all recognize the problems.

**Mrs Cunningham:** I think this discussion has been very helpful. I still do not think it would be that helpful in the case of Mrs Hamblen, because I think she would be the front-line person, given what she has described; and I intend to be in my family, under any circumstances. Most parents know the best thing for their kids. They live through night and day when there is nobody there to witness what is happening, and the day anybody takes away the parents’

rights is the day I will be the first one there to defend them.

With due respect to this legislation, I do not think it is intended to do that, but I think it can be extremely complicated when people say: "I don't want you any more. I want a court-appointed guardian." Those kinds of things make it more difficult. Those are the realities of life when you get more legislation, so we have a downside and an upside if it is not used properly.

The bottom line is that I hope, coming out of this committee—it does not usually happen, but it has in committees I have sat on before. If there should be a recommendation coming from parents or the public to change another act because of what we have heard here, we have to do it. We cannot keep piecemealing this stuff. I do not intend to watch it happen.

One of my colleagues, Mr Callahan, who in fact happens to be a Liberal member of this Legislature, has tried in other ways to change things, and when this government was in opposition, they supported him. I hope he gets a chance to bring forth that private member's bill. But I think it is up to these government members, who have chosen to be advocates themselves, when they see that some other act of this Legislature or of this province can be changed as a result of extensive and expensive public hearings we are going through—it is imperative that they bring it forth and use the good advice they have got within a very short period of time to fix things.

There is not a person in this room who does not know somebody who, probably in the last six months, has been turned away from a mental institution and should have been admitted. I do not blame doctors or anybody else; it has to be clarified in whatever legislation is appropriate. In this case, perhaps Mr Wessinger would consider talking about the advocate's responsibility with regard to admittance.

Perhaps if this advocate is the parent and knows best—because I will tell you that this happens with my son at the hospital all the time. Thank God the doctors take my point of view; thank God they believe me. I mean that. But in this instance, maybe an advocate should be given that responsibility too, and there ought to be a discussion at the appropriate time during clause-by-clause. These people are not coming here for the first time in a decade. They have been coming to this Legislative Assembly for 10 years, and we have an opportunity to fix it.

I hope nobody considers this a political speech, because I am speaking on behalf of all of us. I am certainly aware of my colleague from London South, who has the same things in his office as I do, and I am certainly aware of the two Liberal members who have witnessed this stuff at least in the last five years. We have to change it. So I thank you for allowing my dissertation, but you prompted me, and I thank you for being here.

**Mr Fletcher:** Thank you for your presentation, Mrs Hamblen. One of the purposes of this committee and your presentation is so that we can hear things and ask questions, because some of us maybe do not understand. So do not get me wrong when I ask these questions. I am not being aggressive or anything else; I just really want to know.

The first question is, as far as your son is concerned, what gives you the right to decide for your son?

**Mrs Hamblen:** Let me answer a question with a question, which I normally hate to do.

**Mr Fletcher:** I know; me, too.

**Mrs Hamblen:** Suppose you have a relative who has injured himself with a power saw and is terrified to go to the hospital. "No, I'm afraid. They're going to give me needles. They're going to do this; they're going to do that." Are you going to sit back and watch that member of your family bleed to death?

**Mr Fletcher:** That is the answer I expected, because you care for the person in your family. When that person, in your case your son, gets to the hospital and is saying things to the doctors like, "She beats me; she abuses me," who is the doctor to believe? You are saying, "No, he is having an attack."

**Mrs Hamblen:** The training for doctors, and psychiatrists especially, helps them to understand when a person is psychotic or delusional. If they know the person is schizophrenic, most good psychiatrists will recognize that: "Okay, there's something here. I can't take all of this verbatim. There has to be another story."

**Mr Fletcher:** What I am getting at is that when it comes to a doctor, and that is where I think it is a problem—it would be a problem for almost anyone—first, we have human rights and the rights of individuals. For doctors to take a side in any discussion or any argument could be hazardous to their practice. I am not trying to defend doctors and I am not trying to put you in a position of saying, "Well, no, forget everything else, because I agree with what you say."

**Mrs Hamblen:** Perhaps the emphasis has been so much wrapped around rights rather than needs that I sometimes wonder if some people have their priorities a little bit mixed up. If I were to look at other situations, I would stop and say: "Where is my priority? Is it something I want or is it something I really need?" I have to learn to distinguish, and that is what I think the challenge would be to our legislators in the introduction of and changes to legislation dealing with all these issues. I think the challenge is to ensure that access to help is available when it is badly needed, and to perhaps put certain needs ahead of rights for rights' sake.

**Mr Fletcher:** And it would have been so nice, as far as you are concerned, had something been done in 1981.

**Mrs Hamblen:** Exactly.

**Mr Fletcher:** Since 1981 you have been living this hell and nothing has been done. Something is being done now, and perhaps it does not address your case as you see it, but it is moving in the right direction right now, I believe, as far as the bills that are coming up now.

**Mrs Hamblen:** I must admit I am very sceptical. I think there are a lot of things in there that will help certain people in other vulnerable groups, but I am very frightened about the way it is going to deal with people with schizophrenia and their families. I was kind of looking at it and saying that I do not see anything here where families

are going to be involved in any decision-making, in any advocacy role or in any advisory committee role. We were going to invite and have people sitting on advisory committees from survivors' groups and this group and that group, and I was not seeing any room for family members.

**Mr Fletcher:** Thank you.

**The Chair:** Thank you, Mr Fletcher. Mr Winner.

**Mr Winner:** I was going to ask a question, but in the interest of closing off this hearing, I will probably forgo that.

**The Chair:** Mrs Hamblen, on behalf of this committee, I would like to thank you for taking the time out to come and give us your presentation today.

Seeing no further business before the committee, this meeting stands adjourned until 9:30 tomorrow morning.

The committee adjourned at 1652.

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Friday 21 February 1992

## Journal des débats (Hansard)

Le vendredi 21 février 1992

### Standing committee on administration of justice

Advocacy Act, 1991,  
and companion legislation

### Comité permanent de l'administration de la justice

Loi de 1991 sur l'intervention  
et les projets de loi  
qui l'accompagnent

Chair: Mike Cooper  
Clerk: Lisa Freedman

Président : Mike Cooper  
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# LEGISLATIVE ASSEMBLY OF ONTARIO

## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

Friday 21 February 1992

The committee met at 0942 in committee room 1.

### ADVOCACY ACT, 1991, AND COMPANION LEGISLATION

#### LOI DE 1991 SUR L'INTERVENTION ET LES PROJETS DE LOI QUI L'ACCOMPAGNENT

Resuming consideration of Bill 7, An Act to amend the Powers of Attorney Act; Bill 8, An Act respecting Natural Death; Bill 74, An Act respecting the Provision of Advocacy Services to Vulnerable Persons / Projet de loi 74, Loi concernant la prestation de services d'intervenants en faveur des personnes vulnérables; Bill 108, An Act to provide for the making of Decisions on behalf of Adults concerning the Management of their Property and concerning their Personal Care / Projet de loi 108, Loi prévoyant la prise de décisions au nom d'adultes en ce qui concerne la gestion de leurs biens et le soin de leur personne; Bill 109, An Act respecting Consent to Treatment / Projet de loi 109, Loi concernant le consentement au traitement; and Bill 110, An Act to amend certain Statutes of Ontario consequent upon the enactment of the Consent to Treatment Act, 1991 and the Substitute Decisions Act, 1991 / Projet de loi 110, Loi modifiant certaines lois de l'Ontario par suite de l'adoption de la Loi de 1991 sur le consentement au traitement et de la Loi de 1991 sur la prise de décisions au nom d'autrui.

#### FREEPORT HOSPITAL HEALTH CARE VILLAGE

**The Chair:** I would like to call forward our first presenter, from the Freeport Hospital Health Care Village. Good morning. I remind you that you will be given a half-hour for your presentation. The committee would appreciate it if you keep your remarks to about 15 minutes to allow time for questions and comments. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Mrs Munoz:** My name is Margaret Ann Munoz and I will be making the presentation. With me today are Dr Peter Naus and Rev Ian Wallace, two members of the ethics committee at the Freeport Hospital.

Bills 74, 108 and 109 aim to respect and secure the right of every Ontarian to make informed choices on matters affecting his or her property, personal care and/or medical care. However, service providers at our long-term care facility, Freeport Hospital Health Care Village, are concerned that the specific provisions of this bill may ultimately undermine their intended benefits, and I would like to present some points to the justice committee on that.

First, we would like to recommend that a thorough cost-benefit analysis be undertaken to assess the feasibility and efficiency of the advocacy system proposed in Bills 74, 108 and 109. This should include a comparison of the relative costs and benefits of the proposed system with those of existing systems for advocacy.

The second point is that the important roles of family members, health practitioners and community members in the lives of vulnerable people should be clearly recognized in this bill. I would like to cite an example. It is a personal example, but I was trying to explain to my eight-year-old why I was coming here today. His feelings were that family is really important in decision-making, and this bill does not really include or give recognition to what the rights of families of vulnerable persons are going to be.

I can also cite the example at our hospital where for some of the patients who have been there for a very long time, the staff who care for those patients are those patients' families. They are concerned about the care of the patients and really know them very well, and they would like to be considered in contributing to decisions that are made on behalf of the patient.

Individuals such as family members, practitioners and community members should be given meaningful opportunities to participate in the decision-making process through either the Advocacy Commission or the advisory boards, or they should have the ability to serve as powers of attorney.

Additional provisions will have to be established to look at the professional qualifications and abilities necessary for commission members and Consent and Capacity Review Board members to carry out their various functions. Mechanisms will have to be developed to ensure that commissioners and capacity board members perform their duties appropriately, so some form of accreditation process will have to be established.

Also, training and evaluation procedures for advocates and decision-makers will need to be established. From reading the bill, it is very important that we ensure that the decisions made on behalf of vulnerable persons are as close as possible to the decisions these persons would make for themselves if they were capable.

We need to really understand what these persons would choose for themselves, and that may be very different from what is in their best interests. That may be very difficult for someone to do if he or she is not really aware of how a person thinks, what are important values for that individual. It will be important for the advocacy system to be able to ensure that the choices made on behalf of vulnerable persons choices respect what they would choose for themselves.

Another important area of concern is the expediency and efficiency with which the case advocates and public guardian and trustee offices can respond to individual cases. A lot of times at a hospital such as ours, the crisis situations never arise between 9 and 5, Monday to Friday. Patients will go into crisis in the evening or on the weekends, and it will be very important that the advocacy system be able to respond to those issues and be able to meet the needs of the patient in a timely fashion. The legislation will

have to ensure that this system will be available to those individuals on a 24-hour basis.

Individual advocacy and the public guardian and trustee services may be made more cost-effective, less bureaucratic and less cumbersome if they operate on a complaint basis, responding only to grievances from vulnerable persons or from individuals associated with the vulnerable person. This may be an opportunity to look at this in a different manner, if we were to use it for grievance procedures only.

The bill should also use the expertise of institutional advocacy committees to resolve internal cases of consent to treatment or diverse care issues. Ethics committees exist in most hospitals, and there are usually advocacy protocols in place that can help resolve internal cases.

The process for legally arranging guardianship should be less complex than it is at the moment, to ensure that care givers can appropriately observe formal rather than informal guardianship arrangements. Quite often we will have situations where we know who has the informal guardianship and who is the informal decision-maker in a facility, but because of the cost of legalizing that, some families choose not to actually take the time and money to formalize that arrangement.

0950

Also, our ethics committee felt there needed to be some more clear definitions given to some of the important terms that are used in Bills 74, 108 and 109. These include the terms for autonomy. The question in autonomy is, are we only meaning personal autonomy or are we also meaning autonomy as it relates to community autonomy and how that individual responds within the community in which he exists?

Also, the definition of "vulnerable person" needs to be very clearly defined in order to know which people are actually eligible to be covered under these bills. "Partners" is another word that needs a more clear definition as to who is considered to be the partner or in partnership with this vulnerable person.

Another term that needs to be more clearly defined is "treatment." Again, I would like to cite an example for you. We had a patient in the hospital who was getting palliative care, and because of her ethnic background, there were some religious ceremonies she wanted to be involved with as part of this palliative care. This involved rubbing cream on this person's body. The difficulty with that was that this was contraindicated. The person had very bad sores on her body and the question was, were these creams treatment or were they not treatment? That became difficult. Was it personal care or was it a treatment that was going to help the person? It is very difficult to define. Is this care or is this treatment, and what is the outcome expected of this for the individual involved? The outcome for her was to be more at peace with her death and to be able to have completed all the requirements in her religion to be at peace with herself. So for her it was treatment. For someone else it may not have been considered treatment, it may only have been considered as some form of care.

It is also important that we better define the term "capacity."

The reason we felt those particular words needed better definition was to avoid misinterpretation and the unnecessary use of advocates in cases which could reasonably be handled in a more informal manner. So by more clearly defining the terms, we will be able to utilize the legislation in a more effective manner.

Guidelines for managing and resolving situations in dispute between incapable adults, substitute decision-makers and health care providers should be clarified in terms of their prospective roles, functions and authorities as they relate to treatment and care decisions.

Also, Bills 108 and 109 need to give clear and comprehensive provision for the recognition of both living wills and advance directives, and these should delineate acceptable formats in these documents. In long-term care facilities, quite often decisions are made as to what the patient wants in the future, knowing his or her health may be declining. It is important that the decisions that are made are recognized and can be followed through.

The provisions of Bills 108 and 109 restricting the participation of incapable people in research should be re-evaluated to determine the potentially serious impact of these provisions on health care and on the quality of life for persons with incapacitating conditions. Specific areas of research in which proxy consent by a substitute decision-maker is acceptable because of the low risks and high benefits to participants should be distinguished from areas of research where such proxy decisions should not be allowed. The concern in this realm is that there may be a lot of diseases—dementia and Alzheimer's disease are two that come to mind—where there may be some good that could come from research into those health problems. The provisions in this bill which would prevent including incapable people in research may actually prevent us from learning more about how to care for these patients.

It is important that we recognize the ability of hospital and ethics committees to ensure that researchers adhere to legal and ethical guidelines. There may need to be established a peer review system for facilities engaged in research to ensure that the appropriate mechanisms are in place to protect the rights of incapable persons as research participants.

All hospitals have ethics committees, and hospitals which are involved in research are usually involved with a university. Again, their ethics committees and research committees can review the protocols and the proposals for research to ensure standards are being met.

I would like to open the floor for questions.

**Ms Carter:** Thank you for your constructive and thoughtful comments. I just want to deal with what impinges on Bill 74. I feel that what you are suggesting is really in the spirit the bill is meant to be in, if I can put it that way.

Of course, most vulnerable people do have support from family, friends and medical practitioners, and normally that is adequate. The bill is specifically concerned with the people who for some reason fall between the cracks, who may have no family or who are isolated in some way, and of course in some cases there can be abuse. There can be families who are imposing things on a person that are contrary to that person's own wishes. So do you not feel we really need to have advocates to cover that kind of situation?

**Mrs Munoz:** I agree with the intent. When we looked at the bill, though, we were concerned that the role of family members and health practitioners and community members is not well defined. At present, the bill does not say what those people can do, so the discussion at our ethics committee was that if it does not say what they can do, maybe they cannot do anything.

**Ms Carter:** I think that is a misunderstanding, because we are assuming and hoping that they will continue to do everything they have been doing. We are just looking at the points where that is not sufficient, where the person is not otherwise accounted for.

Of course, the whole concept of advocacy is that the advocate will listen to these people and carry out their wishes. There is no suggestion of the advocate going in and telling people what is in their best interests, what is good for them; that is not envisaged as being the function at all. The function is to say: "Well, I understand you have some problems. Would you like to tell me what they are?" and to take it from there.

Where we already have advocates in the psychiatric institutions in this province, I believe those advocates are able to respond quite quickly, and hopefully that would be the case in the wider application. On some occasions they can in fact alert a family who may care about that person but are not geographically close or do not necessarily know what is going on inside an institution. I think that is the kind of way it would work: sometimes to augment what a family can do and sometimes because that help just is not there.

**Mr Wallace:** I think one can make an assumption, from the way the legislation is currently worded. This may be an off-the-wall example: an advocate walking off the street into a facility such as ours and randomly checking on who might need the services of an advocate and who might not; in other words, stepping into a situation where there might be no need for advocacy, no complaints having been lodged, and really upsetting a system that may be working fine at this point.

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**Ms Carter:** I do not think that is going to happen. I do not think there will be that many advocates on the ground. The law permits and allows them to go into premises, if they have some reason to believe that there is somebody there who needs advocacy, and have the right to talk to that person privately. Of course, if that person says he or she does not want to speak to them, then that is the end of it and they leave.

**Mr Wallace:** Certainly we support the direction of spelling out more specifically the role of health care providers and family members. The community of those individuals would be added.

**Ms Carter:** I see. There is no intention to diminish that; in fact, hopefully to enhance it.

**Dr Naus:** I would like to respond briefly to the suggestion that the intention clearly is to have advocates make decisions that reflect what the vulnerable person himself would have done had he been capable.

That intention, however, it seems to me, is the ultimate criterion in terms of which you evaluate pretty much everything in this particular bill and in the other two. I worry whether that is sufficiently spelled out. I had difficulty finding any particular spot in any of the three pieces of legislation that stated very clearly that an advocate or a substitute decision-maker had to do whatever was possible to figure out what the person himself would have done had he been capable. Nowhere is that spelled out very clearly except, I believe, in one of the provisions of Bill 108; but I think that gets lost.

**Ms Carter:** No, advocates definitely do not make decisions. That is spelled out in Bill 74. If somebody is not capable of expressing his wishes, then as far as this bill goes that person would not have the service of an advocate.

**Dr Naus:** Then my comment applies with equal force to Bill 108 and Bill 109. Given the importance of this particular criterion, I think it should have been spelled out much more clearly. It is also with regard to the criterion that family members and health professionals who know the person well are important. If I am in the position of a substitute decision-maker and I have to try to figure out not what I think the person's best interests are, which is something we have to get away from, but rather what that person would have done if he or she had been capable, I have to have detailed knowledge about that person. If I as a substitute decision-maker do not have it from the outside, so to speak, I have to get that information from family and health professionals.

One more point: Considering whether or not this criterion had been given enough attention made me a little nervous. When you look at the suggestion around research, if we understand it correctly, vulnerable persons ought not to be allowed to participate in research. How can we know that if the vulnerable person had been capable of making the decision, he or she would not have decided to participate in research? It would seem to me that somebody was making a decision in the so-called best interests of the person.

**Mr Wessenger:** Thank you for your very thoughtful presentation. I would just like to sort of dwell on two areas you have raised. First of all, I would suggest to you that actually this legislation does recognize, in effect, the living will, because powers of attorney for personal care may be acted on even if they are not validated. That is under subsection 16(2) of Bill 109, so we certainly have that provision in the legislation and I think it is very important we do that. I certainly appreciate your concern that the autonomy of patients be recognized.

Second, I would like to assure you that there is no intention in the existing legislation to change in any way the existing law with respect to the question of research. If there is any clarification needed with respect to Bill 109, certainly this committee will be looking at making that necessary clarification.

**Mr Winninger:** You raised the issue of whether Bill 108 squarely addresses the need for the attorney for personal care or the guardian for personal care to reflect as accurately as possible in his or her decision-making the wishes of the vulnerable person.

I would ask that you perhaps revisit section 63 of Bill 108, which sets out very specifically what the duties of the guardian and attorneys for personal care are, in particular subsection (3), which says:

"The guardian shall make decisions on the person's behalf in accordance with the following principles."

Not only does it address the wishes a person expressed orally or in writing, but any instructions contained in a power of attorney for personal care: "The guardian shall use reasonable diligence in ascertaining whether there are such instructions or wishes," and deals with situations of inconsistency or no instructions or wishes.

If you can come up with a proposal that might spell things out even more clearly, I am sure we would take a look at it with deep interest. In the meantime, I suggest to you that section 63 goes further than we have seen in other legislation with regard to ensuring that the vulnerable person's wishes are authentically carried out.

**Dr Naus:** My concern was not that it was not going further. This is what my concern was: First of all, certainly philosophically, I was very much in favour of what this legislation tried to do and I was very much in favour indeed of shifting from acting in the best interests to acting in accordance with the wishes of the person, but that is exactly why I became very—I tried to scrutinize whether or not this was indeed done to the fullest. I was very well aware of section 63, but I was still not totally satisfied. I will look at it again and if maybe I feel I need to try another formulation, I will do that and send it on to you.

**Mr J. Wilson:** A number of the other points you raise have been raised before, so I will try not to ask redundant questions. But I am struck that your number one recommendation, or at least in the executive summary, is that a cost-benefit analysis should be conducted.

It strikes me, as Health critic, and my colleague Cam Jackson, who is the advocate for seniors and social services—we spend almost every day, and this afternoon we are meeting with four institutions discussing exactly this—that as a hospital and as a health centre you are required to do cost-benefit analyses all the time. You have increasing pressure from the Ministry of Health to do more in future to justify in many cases the existence of the services you provide. Do you see a double standard here that the government would take an approach to setting up a new system with no discussion of the cost? When you ask the groups that are in favour of this, the principle is so important that the cost does not matter, which leads me to believe we will set up some sort of half-assed system that probably will not work very well anyway and certainly will not meet the expectations of the groups that are pushing for it. That is a rather biased comment, but do you have any comment to add to that?

**Mr Wallace:** I think the difficulty here is that the cost in this is really unknown. In this day and age our facility, like every other facility, is struggling to keep costs in line and run as efficiently as possible, so there are some fears around this: What is this going to cost, given this day and age of budget restraints and cutting back in services that we consider very important?

**Dr Naus:** The emphasis and the suggestion should be placed as much on the analysis of benefit as on the analysis of cost; that is, the comment should not be understood only as a concern about the cost analysis but also as a concern about having some sort of mechanism to evaluate whether the objectives one has in mind are indeed fulfilled. That is so important, given the fact that this is fairly radical legislation.

**The Chair:** On behalf of this committee I thank you for taking the time out this morning and giving us your presentation.

1010

#### INTERNATIONAL FAMILY NETWORK ON ABILITIES

**The Chair:** I call forward our next presenter, from the Families and Friends of the Handicapped.

I just remind you that will be given a half-hour for your presentation. The committee would appreciate if you would keep your remarks to about 15 minutes to allow time for questions and comments. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Mr Carroll:** My name is John Carroll. I am from Thunder Bay. I am the chair of the Families and Friends of the Handicapped or, if you look at our brief, the International Family Network on Abilities.

First of all, to make a clarification and avoid any confusion, the reason this has come about is that we formed a family-based network in 1985. It was originally called the Families and Friends of the Handicapped, but recently there has been some feeling of consensus or movement within our network that maybe the name has outgrown its usefulness for a number of purposes.

One thing is that some people are not feeling comfortable with the word "handicapped." We wanted to choose a name that reflects more the strengths and special abilities of our family members and the people involved in our network, the abilities that allow us to realize the goals we set, not because of the system but in spite of the system. That is just a clarification on the name.

When we originally formed, the purpose—we have been sort of true to that vocation from the beginning—was to address medical treatment, medical care and medical issues. That involved not only active medical treatment specifically of disabled or vulnerable people but also subsidiary issues like matters of physiotherapy, occupational therapy and the issue of public undressing, which is a major issue in our lives, the issue of using subjects for information or teaching purposes in teaching hospitals—all those types of issues that relate to medical care and treatment. We still consider the major function of our network to address those issues, although lately the whole matter of education has become very important to us and all the other issues that spin off that.

I am here alone today, although I represent a network, and the reason for that is that shortly after talking to Ms Freedman my own daughter had to undergo a medical emergency. She had neurosurgery 10 days ago. As soon as I leave here I have to go back and talk to a neurosurgeon and we have to make decisions, because she is scheduled

for emergency neurosurgery today and for further surgery in another 10 days. I think we have a pretty good grasp on what we speak of.

Basically, before talking specifically to these bills, I want to mention that we have a deep concern. We wonder why all the emphasis is on this proposed legislation when the real needs of disabled and vulnerable people in this province are not really addressed in this legislation.

We have a crisis out there. It is a crisis that has been growing and building over the past two years, especially over the past year. It is creating despair. It is bankrupting people. We have needs that are not being met and yet we are talking about creating comprehensive legislation that is supposed to deal with people who are falling through the cracks. We feel very strongly that existing common law, the existing Criminal Code, the existing medical ethics and principles very adequately deal with those. In the meantime there are not only people falling through cracks, there are people falling down chasms and standing at the edge of the precipice.

We have issues that have to be dealt with. We are talking about substitute decision-making and making medical decisions. In this province we do not even have the right to see our own medical files, never mind the medical files of our children. We do not have that right. When my daughter, two weeks ago, was sent off to surgery and the medical file went with her, it was wrapped with scotch tape and masking tape, so we do not even have those rights. I think we should address the things that really touch our day-to-day living.

To get into Bill 74, the Advocacy Act, we accept and we recognize that, in principle, there is merit in this type of legislation, in the idea of advocacy, but as it is written, we have a number of concerns. As a family-based network, they would basically fall into the area of where the family comes into that. We feel that the bill is more effective in establishing the powers and the rights of the advocate than in protecting or establishing the rights of the vulnerable person. We also feel very strongly that Bill 74 as written has a tendency not only to usurp or undermine the role of the family but to come between that very special relationship that exists among family members.

We hold very strongly that in those types of situations we know our family members best; we love our family members best. We understand what they need. We understand their hopes and their dreams, and I think we are in a better position to express those.

We also have another concern about this whole creation of another systematic level of bureaucracy that is going to place more obstacles and create mazes in our lives.

I am not prepared to say that the Advocacy Act should just be discarded. I would recommend to the committee that I do not think Bill 74 should proceed as a piece of companion legislation to Bill 108 and Bill 109. I think the ramifications are so significant that to wrap it up in an omnibus bill type of package really does not do justice to the people and the organizations that may have an interest in or that may be seriously affected by the legislation. It should be broken apart. It should be studied at another time by a committee so that detailed submissions to that bill can come forward, rather than having it just part of one big parcel.

In direct relation to the Substitute Decisions Act, we consider it to be an alarming proposal. We consider it to be a chilling proposal. We think that mechanically, the way it is written, it is fundamentally flawed. It is an invitation to open up a whole maze of legal tangle and court challenges. We go right back to our first and original position that the situation we find ourselves in right now is that we see doors being slammed shut. There is a growing apprehension among the disabled community. We cannot even access the medical treatment, care and services that exist today on an equitable level. I think there is a real, growing sense of apprehension there of the whole intent behind Bill 108.

#### 1020

I just want to bring your attention to page 4 of my brief, because it has been said much more eloquently and much more truly than I could ever say. This is a letter written by Carol Gill, who is a psychologist, and she wrote it in *The Disability Rag*, which is a major disability publication. I am just going to run through it, because we feel it is very important, and it is the basis of our premise. She says:

"What can be more crucial for disabled people to address than the growing numbers of us succumbing to society's encouragement to die?"

"I agree with Ed Roberts that society is killing disabled people and then acting like it's doing us a favour. The corollary is that society offers us only one choice and then acts like it has defended our personal autonomy. In truth, our right to choose life over death is snuffed by society's unwillingness to fund attendant services, access to technology and non-discriminatory suicide prevention.

"When I first plunged into this issue because of Elizabeth Bouvia seven years ago, I was often asked if, in my judgement as a psychologist, I felt right-to-die rulings would influence more disabled people to choose death. I remember how many people disagreed with me when I said such cases would establish a climate in which more and more severely disabled people would be pressured to give up. Now it's happening.

"It's time to pull out of our denial. Our great and good benefactors are not protecting our welfare, our privacy, our dignity, our freedom of choice or anything other than our despair. Those of us with severe disabilities who need human and technological assistance—yes, who need other people's money—are already on death row. What a fix! We're too broken and confused to appeal the execution, and society won't even provide funds for an aide to feed us our last meal. On second thought, I bet they would scrape up the money for that."

If you go to page 5, there is just another little thing I want to cover specifically. The organization that I represent today joins its voice with the Association for Persons with Severe Handicaps, TASH, the Association for Retarded Citizens, ARC, and the United Handicapped Federation, UHF, among others, that recently passed a resolution opposing "the approaches now taken...which authorize third parties to decide on behalf of an incapacitated person that it would be in the best interests of that person to die rather than live with a disability."

One of our major concerns—it is dealt with on page 5 and into page 6—is that Bills 108 and 109 allow for the

denial of nutrition as a form of medical treatment. We are adamant that nutrition is not a form of medical treatment. It is a basic human right; it is a means of providing the body with nutrition. The reason we say this is that we know that within our organization there are many people for whom nasogastric feeding is a daily routine. It is an everyday part of life, it is the way some people have to eat, and our concern is, if that can be defined as a medical treatment, then what about our catheters, our shunts, our suctioning tubes? Physically, they are the same as a nasogastric feeding tube; they are plastic tubes. Can they be defined as medical treatment and taken away from us?

That has a direct impact on a number of things, because right now, within the educational system, there is a whole debate centring on the area of catheterization, a little plastic tube. Is that a medical procedure, which some people hold it is, that requires nurses to come into the school, or is it, as we contend, merely a normal part of the child's toileting, even though he toilets in a different manner from other people? We hold that nasogastric feeding is the same.

If you look at institutions, even provincial institutions, nasogastric feeding is common, not because it is medically necessary but because it is easier, it is cheaper, it is faster to feed patients that way, and the alternative is to spoon-feed. Does spoonfeeding then become a form of medical treatment?

We have deep concerns about those issues. We do not feel that they have been specifically or adequately debated surrounding this legislation. We do not feel that consent is directed towards specific acts in the legislation.

A good example of that is that we know a number of mainly young and healthy people who have suffered disabling spinal cord injuries. They have become paraplegics or quadriplegics. There are exceptions, but almost overwhelmingly the universal reaction at that point and in the hours, the days, the weeks and the months following is that they want to die. They do not want to go on. They cannot visualize living in that situation. Maybe that says a lot about our attitude towards the disabled. Often in that situation, they do brush against death. Very often they have to go on respiratory devices to keep them alive. Yet we know once they get past all that, they are going to get into places like Lyndhurst; they are going to be rehabilitated; life is going to be good. They can do all the things they have always done.

Our two main problems, specifically with Bill 109, are again because of our roots as a family network. We feel Bill 109 undermines the role of the family and comes between the special relationship of family members. Right now, if a person is deemed to lack capacity for informed consent for medical treatment, the current practice is that the physician will go to family members as defined and laid out in the Public Hospitals Act regulations. If those family members are not available, then there is an application made to the district court for a committee of the person.

Our position has been that the declaration of incapacity has always traditionally been the role of the judiciary. We do not feel comfortable that the safeguards built into that system, which has served us well for 100 years, can just be discarded and we can fly on the wings of this type of legislation. We do not feel comfortable with that.

Interestingly enough, to confirm my worst fears, if a person is incapacitated, Bill 109 lists those who may make a decision on his or her behalf. If you will note, they take the same order of sequence from the Public Health Act regulations. The only difference in Bill 109 is that they are given the last priority rather than the first priority. Even if a power of attorney has not been validated, the family can still be supplanted and placed last.

Our major dissension with Bill 109 is that under this bill there are no safeguards, no provisions to ensure that treatment decisions will not be based on non-medical criteria such as quality-of-life or socioeconomic factors. We do not feel that is an unreasonable or unfounded fear, because we know full well those types of decisions are being made now on quality-of-life and socioeconomic factors. We are adamant in our position that perceived quality of life not be the determining factor in whether medical treatment is granted or withheld.

To sum up briefly, our recommendation is take Bill 74, break it away from its companion pieces of legislation and study it as an individual piece of legislation. We submit that Bills 108 and 109 are fundamentally flawed, that they pose a perilous threat to the life, security and wellbeing of disabled and vulnerable persons, and we would ask that they be immediately withdrawn. Thank you.

**The Vice-Chair:** Thank you. Each caucus has approximately three minutes. Mr Poirier.

**Mr Poirier:** Thank you for coming forward. I can see where you are coming from. I respect that. I have no problems with that. It is just that this week there was a document leaked to the opposition that said the passage of these bills is the government's number eight priority out of a very long list. The justification for that, it is said, is because the government has to honour its commitment to the disabled community.

Some people say there has been a lot of consultation, and when I look at the criticism you and your group make of this, you are quite correct. It makes one wonder. I have no doubt they consulted, but if I were a government member and I was listening to you this morning and I saw this, the justification for your criticism, I would want to put on the brakes and say, "What the hell are we doing?" We have good intentions of course but sometimes the intentions—I do not know. This is a very severe criticism when people feel this way about a bill, no matter what the bill is, no matter who is making the criticism, no matter who is in government.

1030

Like I said, we in the opposition want to make sure that some bills are going to come forward. We are not obstructionists. We want to support the principle of it like you do also, but in the details there is something really flawed, according to you and many others. Your vision of this is definitely, wow, strong. It is very strong.

While I was trying to listen to you I was also trying to look through this here. I was looking for some specific points you might want to improve on, but when I really listen to what you say and I look at your bill, "just open the

window and chuck it out and start all over again" is more like what you feel.

**Mr Carroll:** Exactly.

**Mr Poirier:** I can only encourage the government members to get together with you and your group and other groups who feel this way and look at that again and say, "With all our good intentions, is what we want to do really going to please"—if you in your group are not one of the people right on the front line of disability, who the hell is? I am concerned when I hear people like you and your organization say "Just chuck it out the window." Is this the result of consultation?

I am glad you brought it forward. It is sad when some people come forward—I am sure you are not very happy about coming here today and saying "Chuck it out the window." I am sure that is not what you wanted and that is not what you thought this was going to do for you and your family and your friends and the whole community. I am sure this is not what you expected. Correct me if I am wrong, but you were very clear this morning. It also puts a brake on me as to how often—do we do a maypole dance to celebrate this or what? I just wanted to make that comment. I am glad you brought it forward. I will stop here.

**Mr J. Wilson:** Mr Carroll, I do appreciate a number of the concerns you have brought forward. In the brief time I had, though, I have not had time to fully absorb your thoughts on page 8 and to the end of your brief, which is the second point regarding Bill 109 which would sanction non-treatment decisions based on non-medical criteria. As Health critic I am familiar with some of the arguments here but can you in a minute or less in layman's terms tell me how the bill would do that?

**Mr Carroll:** The bill would do it specifically because, first, it creates an atmosphere that leads up to that type of decision-making, and second, it does not specifically say that medical decisions will be made on medical grounds, not on non-medical grounds, such as the ones I have listed there. What it effectively does is if we are in a situation where a medical decision or recommendation comes about that is based not on medical grounds but we feel there is a real matter of rights and autonomy being in question here, the way it is right now there are provisions. There is a mechanism you can go to and you can instigate proceedings that can either challenge that or can trigger a mechanism that will protect the rights of the individual.

The fear is that when you have legislation like Bill 109 all of a sudden there is a superseding piece of legislation that does not explicitly say that those types of things cannot occur and so your right to dispute it is therefore negated and neutralized.

**Mr J. Wilson:** I understand your concern. I am not convinced at this point that is what the bill would do. Though I am not a big fan of the bill, in this particular area I will have to think about it a little more and perhaps the parliamentary assistants will want to make some comments when it is their turn.

**Mr Malkowski:** Thank you for your presentation. There is something I would like to clarify. On page 3, the first paragraph, I would like to quote a couple of your

lines. You say, "It is capable of stripping any semblance of autonomy that a vulnerable person may have." Could you show me where it would say that in the Advocacy Act? I feel that is in total opposition to what we are talking about.

**Mr Carroll:** I am sorry, I do not have the act in front of me. But I think in referring to the whole spirit of the act, it does that because the act, in my opinion, places more emphasis on creating decision-making powers for the advocate rather than leading to autonomy for the individual. Again, I go back to my position that the principle of advocacy has merit, and our position is that Bill 74 should be looked at separately rather than carried in an omnibus package.

**Mr Malkowski:** Then you would agree that the Advocacy Act would perhaps help to give the vulnerable person the power to make decisions and perhaps help those people who do not have family or relatives. Do you agree that the Advocacy Act would help that group?

**Mr Carroll:** I agree that the spirit contained within the act could do that. I think it needs some improvement. It needs more time to be looked at and talked about and improved, but I think the spirit could do that and it may very well be a positive thing.

**The Chair:** Mr Carroll, on behalf of this committee I would like to thank you for taking the time out for your presentation.

I will call forward our next presenter. I would just like to tell the committee that there has been some concern about the time allotment to each caucus, so we will be more rigid on the time allotment now.

**Mr Winninger:** On a point of order, Mr Chair: I do not believe that our side had equal time with the opposition parties in that particular question period and I think it is quite obvious, given the amount of time Mr Poirier spent, the amount of time Mr Wilson spent and the short time Mr Malkowski spent, that this time should be more evenly allotted between the parties.

**Mr Morrow:** As I was the acting Chair at the time, I will answer that. I informed each caucus that it had three minutes. I stood to a strict guideline, and I am sure Mr Poirier will note that after three minutes had elapsed I moved to Mr Wilson. Mr Wilson took three minutes, and I watched the clock with Mr Malkowski and he took exactly three minutes.

**Mr Ruprecht:** I do not think we should be too tough on the Chair. It will all come out in the wash at the end of the day.

**Mr Winninger:** Thank you for your comment. I just wanted to make sure the clothes came out clean.

**The Chair:** As I was saying, there has been concern about the time allotment, and there is equal time allotted to each caucus.

1040

COUNCIL ON AGING—OTTAWA-CARLETON

**The Chair:** Good morning. I just remind you that you will be given a half-hour for your presentation. The committee would appreciate it if you would keep your comments

to about 15 minutes to allow time for questions and comments. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Mr Aubut:** Thank you very much. I was a bit concerned about the time. I thought this time being used now was being deducted from ours.

My name is Germain Aubut. I am from the Council on Aging—Ottawa-Carleton, and I am assisted by Charles Scott, who will be making the presentation. We are very pleased to have this opportunity to present our brief to your committee.

Our brief was submitted to you in September 1991 and was developed by a task force chaired by Mr Scott here. The task force was composed of members of the Council on Aging, the Social Planning Council of Ottawa-Carleton, as well as representatives from service-providing agencies and individuals interested in advocacy issues.

The Council on Aging—Ottawa-Carleton has a membership of 39 persons and is equally divided between seniors, specialists in the field of aging and community agencies providing services to seniors. Our objective in life is to provide planning and coordination of services to seniors in the Ottawa-Carleton area. Our council seeks to enhance the quality of life for all seniors, whatever their religion and cultural and ethnic background so that they may have an equal opportunity to achieve full potential and to contribute to their wider community.

Concerns affecting aging are dealt with by us through various committees including community support, health issues, economics of aging, recreation and leisure, affaires francophones and multicultural issues. The council, incidentally, is funded by the Ministry of Community and Social Services, the United Way of Ottawa-Carleton, the city of Ottawa and the regional municipality of Ottawa-Carleton. With this, I would like to introduce Mr Scott to make the presentation.

**Mr Scott:** Mr Chairman, the Council on Aging commends the government for introducing these bills, as it also commends the member who introduced two initial bills. We believe these represent considerable improvement over existing law and make legal provision for a number of situations where a law has been lacking or unclear. We are pleased the bills provide a legal framework to ensure respect for the wishes of individuals, particularly regarding personal care as expressed when capable.

Although the bills are of general application, we believe seniors will be a very important segment of the population who will benefit from them.

We also believe that some of the provisions are unnecessarily complicated, intrusive, even restrictive and costly. We recognize the desirability of safeguards, but we are concerned that normal family relationships and support be not imperilled. As M. Aubut has said, we welcome the opportunity to come before you.

Dealing first with the Advocacy Act, we started our study with the report by Father O'Sullivan, *You've Got a Friend*, which recommended shared advocacy, a sharing of responsibility among government, volunteers and community groups. He stressed the need for community involvement,

a team approach of full-time advocates working with volunteers. He recommended an Advocacy Commission, which of course is coming in the bill before you, and he also recommended the establishment of regional offices managed by community-elected boards of directors. The shared advocacy model was to be an evolutionary, slow-growth model which might take several years of gestation.

We would like to see that, from the beginning of the program, it would be more closely aligned with that recommended by Father O'Sullivan. Our concern is that if at the outset the advocacy system is centralized and institutionalized, it may remain cast in that mode.

With Father O'Sullivan we believe that an effective advocacy model must be responsive to local needs and resources and must be capable of coordinating and strengthening advocacy initiatives of volunteers. We agree with the Father that the legislation itself should deal not only with the duties and responsibilities of the Advocacy Commission but also the duties and responsibilities of the regional boards of directors.

We feel that in the development of standards and procedures for the implementation of the program, the training and recruitment of advocates and the drafting of regulations, the regional boards may serve as an invaluable resource as a basis for community consultation. Because of the composition and nature of operation of our Council on Aging, as described by M. Aubut, its experience and the experience of our members in advocacy, we believe strongly in lay input. We see the need from the beginning for advocates to be responsive to the regional board. We regard this as particularly important in eastern Ontario, having regard to our cultural and linguistic composition.

Having noted the duties which have been cast upon the advocates, particularly in the Substitute Decisions Act and the Consent to Treatment Act, as well as for systemic advocacy under the Advocacy Act, it is clear to us that volunteers will be required as front-line advocates to develop a personal relationship with the neglected and abandoned, many of whom will be seniors. We are concerned that with their other responsibilities, the advocacy coordinators and the paid, full-time advocates may not have the time to develop a personal relationship which will make them the compassionate, helping hands for the neglected and abandoned. Therefore, we feel that the position of the volunteers should be more fully recognized in the legislation.

We believe that advocates and those involved must be explicitly cautioned against opposing inappropriate standards, and we feel that the local lay input will assist in mitigating any such tendency.

Our last comment regarding this bill concerns the membership of the Advocacy Commission. A majority of its members are to be persons who have or have had a disability, illness or infirmity. We think it unlikely that any of the frail elderly would be able to act as members of this commission, and if so, they would not be represented on that majority while, as we see it, such persons would form an important group of clients.

Of the eight persons to sit on the appointments advisory committee, six are to represent organizations representing persons with disabilities. Only one is to be a seniors'

representative. We consider that the membership in the appointments advisory committee should have more flexibility, and membership on the Advocacy Commission majority should be open to members of the families of vulnerable persons.

Let me turn to the Substitute Decisions Act. We have concentrated on those parts of the bill which deal with powers of attorney for personal care because they are an innovation in the law and they are of particular concern to seniors.

Legal recognition that one may delegate to another the right to make decisions concerning one's personal care will regularize and make legal in statutory form what has been happening in the real world. This power confirms, strengthens and extends the acknowledged right of a competent person to control his or her body. Just as that right is fully, legally recognized—judgements of our courts of appeal, the Supreme Court of Canada—we believe that the full legal recognition should be given to the right of a person, if so minded, to determine who may assist in or make such decisions for one. We believe the right should be exercisable with minimum red tape, delay, cost and stress to all concerned. We feel the giver of the power is the wisest person as to what other person is most likely to follow his or her wishes and to make decisions most in keeping with one's wishes and beliefs.

We cannot support the requirement that a power of attorney of personal care is not effective until it is validated under section 49, nor can we support the validation procedure required by that section. These provisions we regard as an unwarranted restriction on the right of a person to decide who will make decisions for him or her. The need to go through the bureaucratic procedures in section 49 and following, fulfil the ongoing requirements and the costs incidental thereto, may well deter chosen attorneys from taking up the responsibility which the donor of the power sought to give them. Such deterrence may result in frustration of the hopes and desires of the donor when he or she is beyond making new arrangements. Procedure for proxy for health care should be kept as simple as possible.

We are concerned also with seniors. Often deterioration is a gradual process. The senior may be legally capable and yet the helper assumes greater and greater responsibility. Hence, the effectiveness of the power of attorney should not be restricted until there is incapacity, always subject to the express provisions in the document itself. Persons may go in and out of lucidity. There may well be crises of limited duration when there is incapacity. The bill seems to not recognize these situations. It seems to operate on a black-and-white basis, that once you cross the line, there it is.

We recognize the need for safeguards and standards, and there are provisions in that bill which are very excellent, but we think that before there is interference with the power of attorney, there should be some lapse, and there should be an onus of showing errors of omission or commission.

We question the requirement of an annual report because that seems to start on the basis that there is going to be some wrong-doing or sleaze on the part of the person who has the trust of the donor of the power.

We commend for the consideration of the committee, if we may, and of the people who may be looking at this bill further, the Report on Self-Determination in Health Care (Living Wills and Health Care Proxies) prepared by the Manitoba Law Reform Commission, published in 1991. It has simpler mechanisms than seem to be here.

1050

Mr Chairman, I hope I have two more minutes.

**The Chair:** No problem.

**Mr Scott:** Thank you. Consent to treatment: We are asking what difference the legislation will make in the way in which the health care of older persons with deteriorating mental capacity is provided for the patient. What are the changes for the patient, the family and the health care professionals? We wonder also whether advocates will have the training and knowledge to give explanations contemplated by this bill. We think it is very important that the advocates have the training, have the experience, have the background, have the qualifications, because they will play a very important part. That is one of the things we hope the regional boards may be able to help and encourage, the proper qualification of advocates.

Turning to the question of instructions and wishes, which are distinguished in the bill, we are aware to a limited extent that the common law now recognizes advance directions, a signed written statement having been found to be adequate. I would remind the committee of the decision of the Ontario Court of Appeal in Malette and Shulman. We consider the method of giving health care direction should approximate that of the common law. However, because of the inherent lack of reliability with one person recalling another person's prior oral statements and the importance which the matter can assume, we hope oral health care directions will not be allowed to override written directions. We feel that health care directions given in writing and signed by the maker should have priority.

Section 18 of the bill provides that a person who assumes responsibility for giving or refusing consent on an incapable person's behalf is entitled to receive all information required for informed consent. We believe this provision should be clarified and, if need be, extended to state that the proxy may have access to all records concerning the incapable person and his or her treatment on an ongoing basis to the same extent as the incapable person would have. The proxy should also be entitled to have full access to and information from all health givers.

Last, we wish to reiterate a recommendation which we made to then Attorney General, February 1, 1989, that when these bills are brought into force there should be a public awareness campaign. It should include printing and distributing of clear and readable pamphlets in plain language in a number of languages to inform seniors and others about this new legislation, particularly the importance of powers of attorney for personal care and property and giving of health care directions. We hope there may be drafted some simple forms for health care directions and powers of attorney which may be of assistance to people providing these arrangements on their own and, if I may

say so, without the intervention of too many lawyers, being a lawyer myself.

**The Chair:** Thank you. There will be about five minutes for each caucus.

**Mr Poirier:** I will try and do my laundry within five minutes so the government members do not end up with soiled sheets. Maybe you do not want, Mr Scott, to make sure this becomes a manna from heaven or nirvana for lawyers, but thank God you are a QC to be able to understand all that and make some recommendations. I am glad the Council on Aging has pointed out some of the deficiencies. For example, it seems that if you are a senior citizen who is in good health and not disabled or whatever, you get second priority on the Advocacy Commission, from what I read of your criticism of this. I just hope the government members will note this and be a bit more flexible as to who can qualify to sit and the percentage of representation from those people or vulnerable people or people concerned by the passage of these bills. I am glad you brought this forward.

Do you have any more precise feelings as to what you would like to see for advocates—training, whatever; the type of services or how you perceive the advocate to help you?

**Mr Scott:** Speaking for the council, I must respond to the member's question that we have not endeavoured to set that out. We are a volunteer body and there were various statements made during our meetings of the task force and with the council when the task force support came. I do not think I can put anything into words at this stage.

**Mr Poirier:** Have you, as members of the Council on Aging, had a lot of dealing with advocates up till now? Do you have an opinion about the usefulness, importance or relevance of advocates? Have you sat down and discussed this?

**Mr Scott:** No, but we do support this because there is another task force of the council dealing with elder abuse, which we think is a very significant subject.

**Mr Poirier:** Sure is.

**Mr Scott:** I am on that task force, though I am not the chairman of it, and out of that study, I believe the advocates there could be of very great use. This is why, when first the Advocacy Act came out and we saw it—that is why the council was also very supportive of Father O'Sullivan's report. I think it is fair to say our position is fully in support of advocacy. We would like to see it brought a little, shall we say, closer to the people. We think these people can be real helping hands and that is what we want to see; what they are doing. We are afraid the other acts are going to take that away, and that is why we like to see the volunteers emphasized.

**Mr Poirier:** Thank you. Do I have another 30 seconds?

**The Chair:** A minute.

**M. Poirier:** Good enough.

Je vais en profiter pour vous dire, Monsieur Aubut, que la prochaine fois que vous allez venir faire une présentation dans ces pièces-ci, vous allez probablement vous apercevoir qu'il va y avoir un kiosque d'interprètes. On pourra vous parler dans les deux langues. Nous avons déjà la salle 151 qui a un service d'interprètes, mais on n'a pas pu

avoir la salle aujourd'hui. Donc, prochainement il y aura un service d'interprètes dans toutes les trois salles et on pourra se parler dans la langue de notre choix.

**M. Aubut :** J'apprécie ça et j'apprécie beaucoup vos commentaires. Merci.

**Mr Poirier:** I just thought I would share with M. Aubut that we shall have an interpretation service in these fine committee rooms 1 and 2 in the near future.

**Mr J. Wilson:** Thank you for your presentation. I note with interest that the Liberal Party has now changed its position with regard to QCs. I am very pleased to see that. I would be happy to give the next four and a half minutes, Mr Chairman, to the government, because I find that every time I give them lots of time it better strengthens my position with regard to this legislation. But Mr Jackson, in all seriousness, does have a question.

**Mr Jackson:** I would like to commend your comment about communicating. You can bet that the government will spend large amounts of money on advertising, but it is the nature and direction of that advertising. I certainly would like to underscore large print, which is a feature that should be clearly enunciated on your behalf. I know that was implicit.

I have a question for you. I am disturbed about two trends. I will share them with you and then you can react to them. I am concerned that the Advocacy Act is being bundled up with a series of other bills at a time when we are seeing age-sensitive decisions for cutbacks in health care, age-sensitive cutbacks or rights to access to certain medical treatments in this province. That creates a challenge. Since that is on the agenda, I would like to know how you have looked at the Advocacy Act and how that will impact an advocate's role in terms of pursuing medically necessary treatment that may or may not be available.

The second trend which disturbs me is the current dialogue on long-term care reform and why there is no discussion within that framework dealing with these issues. I have been raising it for two years. I am getting a blank look from the ministry and ministry personnel, but they are now at least admitting there are no discussions currently being undertaken with respect to long-term care reform and the unique challenges of community-based home care alternative decision-making in the family setting for frail elderly citizens. That concerns me greatly and if we are to look to this legislation to give that other whole policy direction guidance, where is the linkage? Could you please comment on those two concerns?

1100

**Mr Scott:** Perhaps I will leave to Mr Aubut about the long-term care.

**Mr Aubut:** I will comment on the long-term legislation. The document that has been issued so far is referred to as a consulting document and I do not think it has gone as far as we can expect when they get to the stage where they write legislation. But the essence of these, if you recall, is going to be the creation of advisory boards. We could see these instruments and we hope they will be represented by a lot of seniors; for example, in our case, where they could bring forth the complaints or neglects of seniors to the

authority through the process of this board. We are concerned this time, and this is where we are in the process of our study, as to what authority and liberty these consultative or advisory boards will have to transmit the complaints of the people affected to the proper authority in terms of range of services and ability to be listened to for complaints of a personal nature, such as was implied though this.

On the first question, I do not have any particular points.

**Mr Scott:** I am sorry, I do not think I really can help in that way.

**Mr Winninger:** I for one found your presentation extremely helpful. I note that you support the general thrust of the legislation, but you have also made some excellent, constructive suggestions to make our legislation better. You note that seniors often experience a kind of gradual deterioration that has to be looked at, people who lapse in and out of lucidity. We certainly need to look at that and how we can respond to those situations. I think you would agree with me that if an attorney is perceived by the grantor of the power of attorney to be carrying out actions contrary to what the grantor of the power intended, it might be a situation where validation would be warranted, or where there is complaint from a third party that there is some perceived conflict between what the attorney is doing and what the grantor is doing that might call for validation. Would you agree those are the kinds of situations that require validation?

**Mr Scott:** Even more than the validation, that requires the invoking of the procedure by which the attorney is superseded. We are concerned that before anything can happen, you have to go through this.

**Mr Winninger:** Thanks very much, I appreciate it.

**Ms Carter:** First of all, I also appreciate very much your general support for this legislation and your constructive criticism of it. We agree with what you are saying on page 5 of your presentation, that there is a danger for professional people to impose their values on vulnerable people. I would like to point out that is why we have designed this system in such a way that it is going to be consumer-run, it is going to be representative of the people who are going to be receiving the services. For example, subsection 6(1) says, "A majority of the commission shall be persons who have or have had a mental or physical disability, illness or infirmity." Of course, we have those categories under section 15 for the people who are going to be on the body that chooses the members of the commission.

We have also made allowance in clause 1(d) "to take into account the religion, culture and traditions of vulnerable persons." I hope that, although we see those as very valid questions, they are taken care of in the way we have set this up.

**Mr Scott:** We would like to see more flexibility in the setup of both these bodies.

**Ms Carter:** How would you see that being achieved?

**Mr Scott:** The Advocacy Commission is to have a majority of these people. We would like to see perhaps included in there, as we suggested here, members of the

families of vulnerable persons. Otherwise, as we have said here, we do not see that any of the frail elderly—who is frail and who is not? M. Aubut and I are not frail. We are concerned that the frail elderly will not be able to represent themselves on this commission.

**Ms Carter:** I think that by definition, anybody who is too disabled would not themselves be able to be on it, but as you know, we do have a provision for elderly people as such to be on it. I think there is also a provision that the minister can, if she wishes, set up her adjunct committees which could, for example, have memberships in families.

**Mr Scott:** But we would like to see them right in the centre of the operations.

**The Chair:** Mr Scott and Mr Aubut, on behalf of this committee, I would like to thank you for taking the time to give us your presentation this morning.

ANGELA BROWNE

**The Chair:** I would like to call forward our next presenter, Angela Browne. You will be given half an hour for your presentation. The committee would appreciate it if you would hold your remarks to about 15 minutes to allow time for questions and comments. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Ms Browne:** My name is Angela Browne and I come from St Catharines, Ontario. I am speaking as an individual; I am not particularly representing any group. I have taken an interest in these three pieces of legislation for some time. I have done a little bit of work on them and I would like to share my opinion. I have a written presentation that I just gave to the clerk, so I hope everybody has a copy.

To start my presentation, it is called Summary of Issues Regarding Bill 74, Advocacy Act, 1991, and Companion Legislation.

A couple of weeks ago there was a death in my community. The victim was a psychiatric survivor. During the summer he was given Prozac for treatment of depression. As with many people, he suffered adverse effects, became manic, agitated, sleepless and spent all his money. I remember seeing him so frightened by all this. He questioned the drug and wondered whether the drug company could or should be held liable for causing him to do this. He was also thinking about suing his doctor. Though he questioned his doctor, he did not feel strong enough to carry out any action. At that time he badly needed an advocate.

In the fall he started to crash. Naturally, what goes up must come down. By mid-January or so, he hit rock bottom. He admitted himself to a psychiatric hospital ward only to be let out too soon with the aid of Prozac once again, despite his known history of bad side-effects with the drug—and by the same doctor. He subsequently killed himself.

This was not the first time and I am sure this will not be the last time. I ask honourable committee members today, how many more people like this have to die before somebody finally decides that too many people have died and we have to do something about it?

A close friend of his recently advised me that this fellow hated being poor. He hated having to demean himself by

depending on food banks and social assistance. Like probably the vast majority of people listed as vulnerable in your legislation, he wanted to participate in his community, but attitudes that functionally limit the extent to which disabled people can take part in deciding their own destinies have existed for a long time and to a very large extent they still do.

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Thinking back to his questioning of his doctor, the drug company and the drug, I find it very unfortunate that few Canadian doctors have ever been held legally liable for malpractice and negligence at the same rate they have in the United States. Even if he had lived and he had sued, he would probably have lost. Where does a vulnerable person go? What does a vulnerable person do when doctors seem to tell him how wonderful these drugs are? Is this informed consent, especially when he knew deep down inside that something else had gone wrong, something that no pill could fix? If they cannot speak for themselves for whatever reason, somebody needs to be there to help them and to make sure their concerns are heard. I just hope this person who does speak for them is somebody who has been through the system and not somebody who pretends to represent them.

Legislation for advocacy, consent to treatment and appropriate substitute decision-making legislation is long overdue, but there are certainly parts of the legislation I have conflicts with; there are other parts I feel are excellent and should go ahead. It is important that this legislation reflect the rights and wishes of the vulnerable persons concerned, and that service providers and health practitioners cannot overstep their bounds in delivering services the person does not want and that they make available services the person might want.

Before proceeding into specific points about the aforementioned legislation, I need to introduce myself. I am university educated. I am self-employed. I currently sit on or have sat on several boards and committees on a regional, provincial and national level that dealt with issues of mental health reform, social assistance, women's rights and other things for a number of years. I am an active participant in other areas of my community. I am a published author, having had several analytical papers published through various organizations and in certain publications. I hope to soon finish my book on deinstitutionalization, the failing social safety net and the necessity of a systemic approach to the development of mutual aid and decreased professionalization in the delivery of health care as a whole.

My involvement in mental health advocacy stems directly from my experience as a family member survivor of a suicide as well as a former recipient of services myself as a result of this trauma. To be point blank, I quit using the system because it basically had nothing to offer me. In its stead I kept myself busy and insisted on finding work, and I have developed a wider base of supports around me. If these options were available for my brother at the time or for the fellow who died a couple of weeks ago, I am certain they too would have survived.

Although I support the intent and purposes of the proposed legislation, I find several problem areas that need to be cleared up to ensure that one's right to self-determination

remains just that and cannot ever be interpreted as someone else's right to determine somebody else's future or career, whether that be a career of a medical patient, a psychiatric patient or somebody who is being put under the control of others for whatever reason.

First, I feel that in some respects these pieces of legislation codify many valuable inherent rights, but on the other hand, if some sections were interpreted too broadly, the foundation of these very rights disappears. Second, I find that some parts of this legislation may be difficult to implement given the complexities of the subject matter at hand and the reality of how governments and organizations function. Third, while I see no way of enforcing compliance to the consent legislation, it ostensibly removes liability of health practitioners who follow the law to the letter and in sections pertaining to consent, emergency treatment, failure to find the person who is supposed to seek consent on behalf of someone deemed mentally incapable, and issues pertaining to statements made by apparent family members.

These specific issues will be classed into categories with respect to where they affect general efficiency and undermine the principles that would be emphasized in a piece of legislation like this.

There are some specific areas of concern on the next few pages of my presentation. The first area of concern I would like to highlight is specific training, employment and location of advocates. According to section 5 of the Advocacy Act, it appears that the role of the Advocacy Commission is to promote and facilitate both individual and corporate activities by which persons who are vulnerable undertake to advocate on their own behalf and to establish criteria and procedures for the training and qualification of advocates, and to implement a system of accreditation whereby individual advocates, whether paid or voluntary, can be identified as having the authority to act as advocates within the meaning of this act respectively.

How do advocates get selected? Does this mean there will be appropriate advocates and inappropriate advocates? Would accreditation be linked in any way to funding? Do advocates or agencies that employ them necessarily have to follow a party line to keep their funding and retain their rights as advocates? The concerns inherent in this kind of process are obvious, given that advocacy is effective on an informal as well as a formal level. I feel that community groups vying for accreditation under this act should not have to adhere to any party line, but should instead be guided by a set of generally acceptable ethical and accountability principles, as would any other organization.

How are voluntary advocates going to get regulated? If volunteers must be forced to comply with various rules and regulations set upon them by the province, why bother volunteering? I might as well get paid for it if I have to have that much responsibility. Aside from this, exactly who among the advocates will get paid and just who will end up volunteering? It appears to me that with my experience in community organizations, the professionals get paid and the consumers do it for free. That has to stop. The commission needs to examine issues of accessibility to ensure that paid positions are primarily available to members of vulnerable groups themselves, even if this means that

special training will be provided and accommodations must be made. Because people with disabilities are economically disadvantaged, expecting them to consider volunteering more of their time is not necessarily an effective way to use their large pool of resources.

Conflicts of interest need to be avoided at all costs. While the Advocacy Act recognizes the importance of independence in administering the act itself by putting the commission at arm's length from government and putting it under citizenship, the funding mechanisms need to ensure that social agencies delivering the services, other than advocacy, do not get funded and do not get accredited under this act. Very often, social agencies themselves are a source of controversy in their treatment of vulnerable persons. The Advocacy Commission needs to be free to provide an advocate to assist a person in dealing with such agencies without worrying about conflicts of interest.

Universality of advocacy services is another problem I would like to highlight. What is going to be done about the most vulnerable among those who might need to access advocacy services now: those who have been deemed incapable and placed in the back wards of institutions long before this act will ever be proclaimed? Can provisions be made to inform all current residents of various facilities about their new rights under these acts? In its present form, it appears one must request an advocate; that is, they must know about their rights prior to being able to take advantage of them. While systemic advocacy might resolve some of this problem, information on this act must be made available to everyone; this means written in plain language, in Braille and other methodologies so that people with disabilities can understand them and it is accessible to everyone in institutions and outside them. This means you have to go before the boss of the institution.

What about vulnerable people under the age of 16 years old who wish to obtain the services of an advocate? While recognizing that child welfare regulations apply in this instance, can there be an integration of these acts to allow a role for advocates in this system as well? Many young people have experienced horrific abuses in residential institutions and group homes presumably protected by the Child and Family Services Act. Where do these people turn to for help?

Accountability of the advocacy program is the third issue. While a comprehensive system of advocacy is developed on positive principles, it too could become bureaucratized and ineffective in time. How can we maintain these general principles while allowing for flexibility to serve changing needs? I suggest a regular turnover of people appointed to the commission and that appointments not only come from within established groups. In any social movement, particular party lines develop which may serve the membership of specific groups to which this entails, but reality remains that the vast majority of vulnerable people are unorganized; they do not belong to groups. Who is going to represent them on these commissions? Opportunities need to be built within the selection process to allow persons to choose not to join specific groups but to still have access to the Advocacy Commission if that is what they so choose. This allows for a mix of fresh faces and more experienced advocates,

thus proposing a more representative sample of the vulnerable population.

Although the commission is at arm's length from government, it should be accountable to the Legislature. They should produce an annual report which would be presented to the Legislature through the Minister of Citizenship. This report would include a summary of each year's activities, expenditures, staffing and other issues relating to the general operation of the commission and be made available to the general public wishing to question.

A mechanism should be in place to ensure that individual advocacy commissioners are fulfilling their roles and responsibilities as prescribed by respective legislation, and some input from the community they serve should be made available. In turn, each commissioner should be remunerated for his time as well as reasonable expenses incurred in carrying out his duties.

#### 1120

The fourth issue I need to highlight is the dominance of the medical model in the Consent to Treatment Act, 1991. It appears the act removes judicial review from the initial stages in determining competency. At any given time they can put new health practitioners in the regulations, and these people will have the power to say you are competent or incompetent at the beginning. This gives them a lot of power. Any health practitioner prescribed in the regulations has the power to determine this, supposedly based on specific criteria that have yet to be listed. I am sure it will be based on the Weisstub commission, into which I had some input.

Let us suppose the criteria for capacity do get established. How can we ensure that these criteria for determining capacity are always adhered to when making treatment decisions? Ask any psychiatric survivor who experienced the Mental Health Act and one will find that this is not always adhered to. Very frequently capacity is equated to agreement with the doctor and his treatment plan prescribed for them. Have we heard of many cases where a patient agrees with the doctor and still gets ruled incapable to consent to treatment? Certainly not. They agree with the doctor; they are automatically competent. It is interesting.

Certainly in these circumstances one has the means to challenge the decision. The first stage would be the Consent and Capacity Review Board, modelled after the regional review boards under the Mental Health Act. I am concerned that medical representation on this board could bias the review process. While I have no problem with having a special advisory committee to the Consent and Capacity Review Board that would include qualified medical as well as other specialists in the area of mental capacity and assessment, I feel the board should be free of health practitioners. Studies have shown most medical doctors are no more specialized in determining competence than the general population, so assuming that a physician is on the board does not assume that he knows who is capable and who is not.

Although one could appeal the decision of this board further to the courts, many vulnerable people would not go this far. Very often in the case of psychiatric survivors, larger doses of drugs are often given prior to the hearing to

make it difficult for the person to follow, thus confirming an assessment of "incapable" by the board because they are so drugged they cannot make sense of what is going on around them.

In accordance with subsection 6(1) of the proposed act, "capacity" is defined as being "able to understand the information that is relevant to making a decision concerning the treatment and able to appreciate the reasonably foreseeable consequences of a decision or a lack of decision."

This definition could be interpreted broadly to supersede one's beliefs and values and rights to alternative models of explanation and treatment. What about those people who legitimately do not believe they are ill, but instead are suffering as a result of poverty and neglect, which might be true in many cases? Look at some of these people who kill themselves in boarding homes year after year. I am sure it is not the psychiatric illness that gets them. Are they incapable because they simply do not believe that taking neuroleptics will help them get a job in the competitive marketplace? What about highly distressed housewives who refuse to believe the root of their problem is an estrogen imbalance? This definition invites confrontation of ideologies, and confrontation should be welcome in a democratic society.

The fifth item is potential abuses of consent to treatment. In section 22, the definition of "emergency treatment" allows treatment without the consent of the person or his substitute decision-maker if the person is incapable with respect to consenting to treatment and the nature of the problem is such that if not treated within 12 hours serious bodily harm will result. This can be interpreted broadly once again, given that serious bodily harm might imply perceived suicidal tendencies or living in a precarious situation whereby external influences could produce harm.

Once again, predicting suicide is not a specialized skill of a physician either. Of persons who had attempted to do this before, under this act I am sure they would be particularly vulnerable to forced treatment in the name of saving their lives, even in cases where in reality no harm would be done if they were just left alone.

Furthermore, what stops a physician from using electroconvulsive therapy against the person's wishes in these kinds of situations? We keep hearing ECT is supposed to be effective in warding off suicidal tendencies. The studies tend to contradict that. In reality it produces a head injury and it produces a temporary euphoria in some patients which merely masks the problem and simply delays the suicide attempt. We all know what happened to Ernest Hemingway.

The Consent and Capacity Statute Law Amendment Act, 1991, affects subsection 35a(5) of the Mental Health Act, which specifies that the board, in this case the original review board, could not authorize psychosurgery or ECT even upon application of a doctor. In the new act the disqualification of psychosurgery is returned, but not for ECT. I suggest that the new act spell out that the Consent and Capacity Review Board be restricted from ever ordering ECT as well as psychosurgery, as previously stated the case.

Cases of permanent memory loss are too frequent to allow ECT, even if it is a small number of cases that would

be ordered by a board with the power to do so. The means to find more effective alternatives to ECT, as well as other forced drug treatments, should be made available as readily as any other medical treatment.

The next section is potential coerciveness in the Substitute Decisions Act, 1991. Under sections 27 and 29, the public guardian and trustee must investigate allegations that someone is not capable of managing his property or taking proper care of himself. If the public guardian and trustee feels that the person is suffering from serious harm as a result of these problems, he could apply to the court for a 90-day temporary guardianship order. If the matter is so urgent that proper due process would delay necessary intervention by the public guardian and trustee, the court has the discretion of dispensing with notice to the subject of the order and granting the public guardian and trustee temporary guardianship for a maximum seven-day period.

Although I feel the intent of this section is supposed to be narrow in its focus for supposedly the severe cases, many of these worst-case scenarios may fall into this category as well as a lot of cases that are not worst-case scenarios, and I feel that over time, abuses would prevail in over-interpretation of this section.

Powers of the court in this regard are quite broad. In section 46, capacity functions are defined as decisions regarding health care, nutrition, shelter, clothing, hygiene and safety. For example, if a person is ruled by the court to be incapable of making decisions with respect to all of those functions, which many psychiatric survivors have been and still are, broad powers can be granted to the appointed guardian. The guardian could force the person to live where the guardian thinks is best, could pick and choose who he sees as friends, if and where he will work and if and from where he will get treatment. The court can further order that this order include that the person can be taken to a psychiatric facility against his will.

Is this a way to shove outpatient committal through the back door? I am sure this will be the circumstance of many people who will fall subject under this act. Is there a potential for this section to be abused by some overly zealous family members or even "neighbours" in sweeping our streets clean of the homeless, the severely impoverished and the undernourished?

Again, I believe the funding for this should be redirected to community-based peer support and other non-profit alternatives. I would rather see a community group get funding to hire special support workers to assist severely affected individuals with a potential to deteriorate in these functions and their activities of daily living than see the money used to enforce the kind of police state function that this can potentially become.

The final point I have on the legislation is regarding immunity from civil suits. In accordance with section 24 of the Consent to Treatment Act, 1991, if a health practitioner administers to a person he or she believes, on reasonable grounds, to have consented to treatment, or refrains from treating someone he or she believed to have refused treatment, he or she is not legally liable for any act or omission in this regard.

If a health care practitioner administers emergency treatment, as discussed earlier, because he thinks that some imminent bodily harm will happen within 12 hours, or if he fails to do so if a person who previously consented did not consent, in accordance to sections 22 and 23 of the act he cannot be held liable for treating a person without consent or failing to treat a consenting person.

Furthermore, if the health practitioner fails to find the proper person to consent or refuse on a patient's behalf after a reasonable search, he is still not liable even if he forced drugs on somebody who really did not want them. I have serious concerns about this as this may encourage a broad interpretation of consent on the part of the physician, and negligence in this regard is unactionable.

This immunity negates the possibility of the court system getting established in providing checks and balances in this regard as well as providing remedies for people who are truly harmed through this broad interpretation of consent or refusal. I suggest that the right to sue be restored in its entirety.

I will be free for any questions any of the committee members might have.

1130

**The Chair:** Thank you very much. You each have about three minutes.

**Mr J. Wilson:** Thank you for coming forward today. I found your brief fascinating. A number of the points we have heard before. Just to play devil's advocate, at the very beginning when you told us about your friend who had died, would he not have been entitled to an advocate in the psychiatric ward of the hospital?

**Ms Browne:** This was not a provincial hospital; this was a general hospital psychiatric ward.

**Mr J. Wilson:** So he was just in the psychiatric ward?

**Ms Browne:** All he would have had access to was a rights adviser. At this time he wanted to stay in the hospital, but he was released only on Prozac.

**Mr J. Wilson:** Do you know of anyone who has had any experience with the advocates who are in psychiatric hospitals now? I know there are not very many. The reason I am playing devil's advocate is that my tendency would be to beef up the system we have, which we have been told is totally inadequate. I have met a number of those advocates and they seem like very decent and very caring people to me. What has your experience been in that?

**Ms Browne:** I find kind of a mixed response. There are some advocates who have worked in provincial hospitals who are very good and truly are advocates; there are others who try to find some way of co-opting the system. I feel that if somebody really does not want to be there, the advocate should fight his damndest to make sure that this person is not there. If the person does not want medication shoved down his throat, regardless of capacity and so forth, and in the case of the incapable the substitute decision-maker decides not to have medication shoved down his throat, then no medication should be shoved down his throat. There should be no override clause in that section.

**Mr Jackson:** Very briefly, I am familiar with the Fram reports, and I am one of those weird MPPs who has actually read the Weissstube report. I still have not yet heard from the government on that issue, and contained in it is some contradictory information about the issue of consent to treatment and a definition of competence.

I am wondering if you can state very briefly for the record if you have the concern that we do not have an adequate definition of competence in this province and yet we seem to be able to proceed with legislation that purports to be able to cope with that. Could you respond to that as it specifically ties to that legal definition?

**Ms Browne:** A lot of these legal definitions that come out say, "you understand the treatment?" Yes, I understand the treatment. I just do not like to be given this treatment because I have very bad side-effects from it. "Do you understand that this helps your illness because it apparently has helped your illness before?"

You see, there is just too much override. A person would be considered not competent if he does not believe he is ill or if he does not believe what the doctors say or does not want to follow their prescribed plan. Some people like nutritional therapy to deal with their problems; some people like to go to a safe house; some people just like to stay at home and stew about it for a while, and that is fine. People should have these absolute options.

I have a real problem when on the one hand we allow a cancer patient to terminate all treatment, even if it results in imminent death, while on the other hand we do not allow the same right for people who are labelled psychiatric patients.

**Mr Fletcher:** You have some concerns regarding the Advocacy Act and who is going to be the advocate and everything else. Some groups have been coming in over the last few weeks, and yesterday one was saying that perhaps what we should do is implement the Advocacy Act and then wait a couple of years before we start implementing the other ones so that all the bugs are ironed out of that act and it gets working and the advocates are in place. Then we can implement the companion acts, and it will be all in place. Is that something that you could consider?

**Ms Browne:** I thought about that. You are referring to having the advocates in place first and having them work and then two years later, after reports from the advocates come back, implementing health consent and all that other stuff.

**Mr Fletcher:** The two years was their suggestion.

**Ms Browne:** Yes, that sounds more appropriate because then you are becoming more aware of some of the issues that would be involved.

**Mr Fletcher:** The one thing that bothers me about that is, as you say in your brief, we have waited that long. We have waited so long for something to come along, and it is finally coming along.

**Ms Browne:** I especially want the Advocacy Act in place. The other stuff I think probably could wait but I really believe that in order to wait, you really have to listen to what the advocates are saying and what the people are saying during the process, after the Advocacy Commission is implemented.

**Mr Fletcher:** We had a motion early in the week from the members opposite that we should just scrap this whole thing and send it back, which would probably delay it a few years—three or four years perhaps. Is it that out of whack that we should scrap the whole thing?

**Ms Browne:** No. There are some valuable parts to the legislation and they should be maintained. If it does get sent back, something worse might come back in, so I really feel that the Advocacy Commission needs to be implemented immediately.

**The Chair:** On behalf of this committee, I would like to thank you for taking the time out and coming and giving us your presentation this morning.

#### CITIZENS COMMISSION ON HUMAN RIGHTS

**The Chair:** I would like to call forward our next presenter, Raymond Mallet. Just a reminder that you will be given half an hour for your presentation. The committee would appreciate it if you would hold your remarks to about 15 minutes to allow time for questions and comments. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Mr Mallet:** My name is Raymond Mallet and I am an investigator for the Citizens Commission on Human Rights.

I appreciate the opportunity you have provided for dialogue and I would like to discuss the consent to treatment proposals in Bill 109, which is being submitted for first reading.

I have worked as an investigator for the Citizens Commission on Human Rights for the past two years and during that time I have become very much aware of the unfortunate position these very vulnerable people often find themselves in. I will provide for you examples of the cases that have come forward with their stories.

Case 1: "I was physically abused through being punched in the face, kicked in the stomach and kicked in the back after I complained about the medication that I was being given."

Case 2: He was assaulted by attendants, specifically being repeatedly punched in the head and forcibly injected while being restrained.

Case 3: "I have experienced as a result from these medications such side-effects as vomiting, weakness and temporary memory loss. In May, I received a change in my medication that resulted in complete memory loss for days."

Case 4: He has received numerous injections of drugs. Side-effects have included Parkinsonism, which is tremors and impaired motor control. He is currently experiencing frequent loss of control of the muscles of his thumbs and hands.

The severe side-effects of the major tranquilizers given at the public mental hospitals throughout Ontario have impaired patients to the point where they can no longer return to their jobs and work for their livelihood.

Case 5: "Following the injections, I experienced vertigo, blurred vision and rigidity of my body musculature. I was a construction worker. However, I am now physically degraded to such a point that I am unable to work in construction."

Case 6: Drugs left him incapable of normal function for many weeks. He now experiences tardive dyskinesia

and a speech impediment and is unable to return to previous employment in sales due to the speech impediment.

Case 7: Side-effects included the inability to control his tongue to such an extent that it causes choking to occur. There has also been increased nervousness and deterioration of eyesight. He has undergone severe physical deterioration and is unemployable. Prior to receiving these injections he was able to see clearly and was working.

In all of the above cases the patients were forced in a brutal, physical fashion to take drugs, sometimes being held down by as many as five or six attendants.

The problem of forcing treatment on a patient who does not want it is eloquently stated by Dr Thomas Szasz, author of *The Myth of Mental Illness* and numerous other books. "Decent, dignified medicine rests on the moral and legal premise that people have a right to reject treatment...but in psychiatry, where there is no real treatment at all—where what's called treatment is dangerous and damaging—they can give it to you involuntarily."

#### 1140

All of the above patients were considered to have provided implied consent to hospital authorities due to the fact that their right to refuse was broken down to the point where they could not refuse the medication any longer.

In the proposed Bill 109, which allows implied consent, the door is opened to numerous possibilities of abuse. This is one of our major concerns with this legislative proposal. We feel that there must be a verifiable written informed consent which should include the following:

All positive and negative results must be provided on a written information sheet for each medication and procedure. This should be written in lay terms and must be fully understood by the patient or his decision-maker if he is incompetent.

The person should have a complete and thorough medical examination to make sure that the psychiatric symptoms that are being manifested by the patient are not the result of some unknown, undetected physical condition.

Illness in psychiatric admissions—the following study was done:

The American Journal of Psychiatry in May 1981 published a paper called *Unrecognized Physical Illness Prompting Psychiatric Admission: A Prospective Study*. It states: "The authors studied 100 state hospital psychiatric patients consecutively admitted to a research ward, who were screened to eliminate physical illness before admission. They found an unusually high incidence of medical illness: 46% of these patients had an unrecognized medical illness that either caused or exacerbated their psychiatric illness; 80% had physical illnesses requiring treatment, and 4% had precancerous conditions or illnesses. A workup consisting of psychiatric and physical examination, urinalysis, ECG, and EEG after sleep deprivation identified over 90% of medical illnesses present in this population. The authors suggest that such a battery be part of the routine workup for all hospitalized psychiatric patients."

They concluded with the following statement:

"Should our friend be unfortunate enough, however, to actually be suffering from a mental disorder, the chance of

correct diagnosis, treatment and effective result become remote."

As concerns competency and capacity:

The definition of competency as per Black's Law Dictionary, 5th edition, is as follows: "The term contemplates the ability to understand the nature and effect of the act in which a person is engaged and the business he or she is transacting; such a measure of intelligence, understanding, memory and judgement relative to the particular transaction as will enable the person to understand the nature of his act."

The definition of incapacity as per Black's Law Dictionary, 5th edition, is as follows: "Such is established when there is found to exist an essential privation of reasoning faculties, or when a person is incapable of understanding and acting with discretion in the ordinary affairs of life."

We believe, in order to fulfil the above definitions, particularly for the purposes of psychiatric treatment, that the person being treated or, if incompetent, his substitute decision-maker must fully understand not only the nature of the treatment but also the origin of the disorder.

Therefore, bearing these definitions in mind, all persons would only meet the incapacity definition because there is no ability for discretion of understanding without a full and complete medical examination.

One could compare the person receiving psychiatric treatment without having all the written information about the nature of the illness and treatment to you or me signing a mortgage document without knowing the interest rate or the amortization period. Not only is this completely irresponsible, but also criminal.

It is vital that this committee—in view of a few of the cases cited earlier, hundreds of others, and the definitions as above—fully understands the need for the initial, thorough medical examination and devises for the purposes of implementation a medical examination form. This would eliminate the personal injury and suffering of so many vulnerable people and would restore dignity, humanity and trust to the mental health system.

In this decade approaching the 21st century, medicine must be directed to wellness; otherwise, the suffering will needlessly be prolonged.

With regard to the charter, in the proposed Consent to Treatment Act, Bill 109, first reading, "implied consent" and "informed consent" were tolerated only because the consequences of these concepts were not fully understood.

In the Canadian Charter of Rights and Freedoms, section 7, legal rights, states, "Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice."

Subsection 15(1) of this charter reads, "Every individual is equal before and under the law and has the right to equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability."

To ensure the security of the person, the prevention of unnecessary treatment punishing the recipient with disabilities and the protection of his right to equality and rights to proper humane care, he must have full written informed

consent, not implied consent or informed consent arbitrarily applied. In order to provide the guaranteed rights per the charter, the recipient of any psychiatric treatment must feel secure and confident that he will not receive any psychiatric intrusion without being aware of the origins of the illness and the nature of the treatment, including any and all physical, emotional and mental consequences.

Therefore we feel that this committee must not allow psychiatric discrimination to override these equality rights. A full and complete medical examination would eliminate the arbitrary and uncertain psychiatric treatments.

Hopefully our suggestions will be viewed as prudent and responsible and will be made a part of this bill in its second reading. Obviously, it goes without saying that this new bill must guarantee the rights and freedoms afforded us in the charter. We thank you for this opportunity to address this committee and voice our concerns regarding these crucial points.

**The Chair:** Thank you very much. Questions and comments, Mr Poirier?

**Mr Poirier:** Would you be able to address what you have just said in light of the current Mental Health Act? How do you relate what is in the Mental Health Act and what is in front of us with the four bills?

**Mr Mallet:** I do not have the Mental Health Act with me, but there are certain sections that were just not being applied. Our concern is that you have the Mental Health Act but there is no application. Particularly there was a section called "psychiatric," that a patient, if he is competent, can refuse psychiatric treatment at any point in time. This did not occur. I have literally hundreds of cases who have been forcibly injected, and we are going to pass another bill. What is the use of passing another bill if you cannot enforce or get the first one applied?

**Mr Poirier:** Let me be the devil's advocate. Why not tighten up the Mental Health Act?

**Mr Mallet:** Provided it is in agreement with the Canadian Charter of Rights and Freedoms, sure. If there are any sections that are in violation of it, it will be challenged and this whole legislative committee will be found to be a waste. It will just be thrown out, because there was a recent court decision in the Ontario Court of Appeal, Reid vs Gallagher. When they were competent they had refused, for example, treatment A. Then umpteen months or years down the road they were incompetent and they were told they had to take that treatment A and they said no. So they went to court and the judge found that, since when they were competent they refused treatment A, you cannot give it to them at any point afterwards if they say no, they do not want it, in a competent or incompetent state.

**Mr Poirier:** Suppose you were given a one-person mandate in a commission to improve or change or whatever you wanted to do with the Mental Health Act. Do you think it could be done to meet your group's requirements or expectations?

**Mr Mallet:** Sure. If everything totally 100% conformed to the charter and there was no dehumanizing or degrading treatment involving electroconvulsive therapy

or psychosurgery, yes, it is possible to grant these people their rights they are guaranteed under the charter.

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**Mr Poirier:** If that came about, would you see that these bills here would be a further danger? Keeping in mind that you have amended the Mental Health Act the way your group would like to see it amended, if that were done, would these four bills be a danger for you?

**Mr Mallet:** As I say, back to the charter, only the points that violate the charter and regard these individuals as lower-class or as crazy or insane, and therefore they cannot say yes or no to the treatments, yes, it would go against it, because everything has to be aligned with the charter. That is the supreme loss of what should be—

**Mr Poirier:** Would it appear that your main concern seems to be the non-compliance or the non-respect of the Mental Health Act?

**Mr Mallet:** Yes.

**Mr Poirier:** Out of 100%, what percentage of that non-compliance is the cause of what your group is studying or noticing?

**Ms Massie-Grellin:** It is very high.

**Mr Mallet:** Extremely high.

**Mr Poirier:** So if we could resolve the problem of non-compliance and close the so-called loopholes of the Mental Health Act, then maybe you would not be in front of us and having to worry about it, right?

**Mr Mallet:** Correct.

**Mr Poirier:** Members of the government have taken note, I am sure.

**Mr Winninger:** I certainly enjoyed your presentation. It reminded me of a time when I was still practising law and I went and argued before a judge that the treatment provisions of the Mental Health Act violated sections 7 and 15 and even section 11 of the charter. I was not too successful. It may have been because of the facts and circumstances of that particular case, but we did spend two days arguing with the Ministry of Health over some of the issues you raise.

I think, however, in hindsight that there is a balance that has been effected under section 34, I believe it was, of the Mental Health Act, that will safeguard the rights of the patient to object to treatment but at the same time ensure that if that patient lacks capacity to consent to treatment, if the patient indeed does not understand the nature of the treatment or the consequences of accepting or the with-

holding of that treatment, there is a very practical objection procedure laid out.

However, I would go so far as to agree with you that in practice, in the administration of the Mental Health Act, often physicians do not comply with the letter of the law. We have heard in previous presentations as well as your own that if the patient refuses treatment, he is deemed generally to lack capacity to consent to treatment, but if he accepts treatment voluntarily, then he is deemed to be capable of consenting to treatment. That is the problem we face. It may be more in enforcing the administration of the act—and we have increased the penalties for non-compliance with these provisions—that we can safeguard the rights of the patient that you refer to.

**Mr Mallet:** We have patients that, the psychiatrists being doctors, can justify their way out by saying, "I forcibly treated this guy, but he needed it." You are comparing a person who is a psychiatric patient, with a bad connotation, to a doctor in the medical field. When you get the two of them together, one does not compare.

**Mr Winninger:** Sure. I just want you to know it is a difficult position we are in, because yesterday or the day before we heard from psychiatric survivors who said, "I need to be assured myself that when I'm delusional and I'm refusing treatment in a hospital milieu, I'm going to get the treatment I need to snap out of those delusions." I would ask you whether you would agree with a provision that would allow such a psychiatric patient to set down in writing what his wishes are if he finds himself in a treatment facility, with a view to having those wishes obeyed.

**Mr Mallet:** By all means. I would go one step further and make it a criminal offence if a person was forcibly injected, because it is assault per the Criminal Code of Canada. Any violation of a person's rights, if it is a violation of a federal law, should be regarded as a criminal offence.

**Mr Winninger:** I see. Thank you.

**Mr Wessinger:** You mentioned the Reid vs Gallagher case. Certainly I would like to point out to you that the Consent to Treatment Act does try to ensure that prior competent wishes are honoured when a person becomes incompetent, so we have addressed that situation.

**Mr Mallet:** Yes.

**The Chair:** Ms Massie-Grellin, Mr Mallet, on behalf of this committee, I would like to thank you for taking the time out this morning and giving us your presentation.

Seeing no further business before the committee this morning, we will adjourn until Monday, March 9, at 10 am.

The committee adjourned at 1155.

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Monday 9 March 1992

### Journal des débats (Hansard)

Le lundi 9 mars 1992

### Standing committee on administration of justice

Advocacy Act, 1991,  
and companion legislation

### Comité permanent de l'administration de la justice

Loi de 1991 sur l'intervention  
et les projets de loi  
qui l'accompagnent

Chair: Mike Cooper  
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# LEGISLATIVE ASSEMBLY OF ONTARIO

## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

Monday 9 March 1992

The committee met at 1028 in committee room 1.

### ADVOCACY ACT, 1991, AND COMPANION LEGISLATION LOI DE 1991 SUR L'INTERVENTION ET LES PROJETS DE LOI QUI L'ACCOMPAGNENT

Resuming consideration of Bill 7, An Act to amend the Powers of Attorney Act; Bill 8, An Act respecting Natural Death; Bill 74, An Act respecting the Provision of Advocacy Services to Vulnerable Persons / Projet de loi 74, Loi concernant la prestation de services d'intervenants en faveur des personnes vulnérables; Bill 108, An Act to provide for the making of Decisions on behalf of Adults concerning the Management of their Property and concerning their Personal Care / Projet de loi 108, Loi prévoyant la prise de décisions au nom d'adultes en ce qui concerne la gestion de leurs biens et le soin de leur personne; Bill 109, An Act respecting Consent to Treatment / Projet de loi 109, Loi concernant le consentement au traitement; and Bill 110, An Act to amend certain Statutes of Ontario consequent upon the enactment of the Consent to Treatment Act, 1991 and the Substitute Decisions Act, 1991 / Projet de loi 110, Loi modifiant certaines lois de l'Ontario par suite de l'adoption de la Loi de 1991 sur le consentement au traitement et de la Loi de 1991 sur la prise de décisions au nom d'autrui.

**The Chair:** I call this meeting of the standing committee on the administration of justice to order. I would like to give a reminder to the committee members that we have been given permission from the House leader's offices to meet on Tuesday, March 24, and Wednesday, March 25, so we will be sitting those two extra days.

### AD HOC GROUP ON ADVOCACY, CONSENT AND SUBSTITUTE DECISION MAKING

**The Chair:** Good morning. For the record, could you please identify yourselves one at a time and, as it is such a large number, could you please speak into the mike. As you know, you will be given a half-hour for your presentation. The committee members would appreciate it if you would keep your presentation to about 15 minutes to allow time for questions and answers from each of the caucuses. Could you please identify yourselves and then proceed.

**Ms Shushelski:** My name is Carolyn Shushelski, and I will be the spokesperson for the group; however, we would like each of us to be introduced to the committee. Perhaps each one of us could just introduce herself and give her designation and the group she represents.

**Mrs Suttie:** I am Jean Suttie, associate provincial director, Victorian Order of Nurses.

**Ms LeBlanc:** I am Barbara LeBlanc, Ontario Medical Association.

**Mrs Phillips:** I am Emily Phillips, president-elect, the Registered Nurses' Association of Ontario.

**Ms Wolman:** I am Harriet Wolman, chairman of the public affairs committee of the Ontario Long Term Residential Care Association and managing director of a retirement home.

**Mrs Beeby:** I am June Beeby, executive director of Ontario Friends of Schizophrenics. I am also the mother of a suicide schizophrenic.

**Ms Wall-Armstrong:** Deborah Wall-Armstrong. I am the owner-representative of a nursing home in Barrie. I am also a vice-president of the Ontario Nursing Home Association.

**Ms Shushelski:** This ad hoc group is a group made up of health care providers and family-based advocacy groups. We came together to discuss mutual concerns respecting the proposed legislation on advocacy, consent to health care and substitute decision-making.

The group represents the Ontario Friends of Schizophrenics, the Ontario Hospital Association, the Ontario Long Term Residential Care Association, the Ontario Medical Association, the Ontario Nursing Home Association, the Ontario Registered Nurses' Association of Ontario and the Victorian Order of Nurses of Ontario.

We are among the principal organizations which will be involved and most directly affected by the implementation of this legislation. We do support the underlying principles of the legislation. We appear before you today to express our shared concerns about the proposed legislation as it is written, and to request that it be deferred pending realistic amendments being made. We ask you to slow down and urge you to give it the time and attention it deserves.

The Consent to Treatment Act is an attempt to protect the rights of a mentally incapable person with respect to consent to treatment and mental competency determinations. However, we believe there is an equally powerful competing principle, which is the right to timely and appropriate treatment. Our fear is that the latter principle will be compromised if this package of legislation passes as drafted. These bills, if implemented, may interfere with assessment, diagnosis, basic care and humane treatment, causing unnecessary pain and suffering. We believe the right to timely health care is an inherent right to be protected, not undermined.

The appropriate role of the family in making consent decisions on behalf of their family members who may be incapable will be delayed or displaced. Relatives, health care practitioners, advocates and substitute decision-makers will be pitted against each other unnecessarily because of this legislation. Rather than establishing a community of interest and support around the mentally incapable person, the

legislation entrenches a series of adversarial relationships among all those I just mentioned. We have tried to work with the government to ensure that the legislation will be practical and not hinder patient care and treatment. In our opinion this legislation is anything but practical and manageable. In fact, it may place patients at risk of harm, this being a result of procedural delays in receiving care and treatment.

Most of the members of the ad hoc group have already appeared before the committee. We have each clearly stated our concerns. Now we understand that the government has drafted amendments to the legislation. We have requested that we be given the opportunity to review these amendments. But to date the government has not made the amendments public. This refusal to share information has made our work more frustrating and less effective than it would have been had we known the substance of the amendments.

The government's failure to table them in a timely fashion has meant that a certain amount of committee and interest group time plus money has been wasted. As well, the credibility of the consultation process on these bills has to be called into question. A patient should have the right to make an informed decision about proposed treatment. We believe that a mentally incapable person should have the right to be assessed, to have a diagnosis established in respect of his or her condition and to receive basic care and humane treatment without delay in all circumstances. We believe that if the bills are passed in their present form mentally incompetent patients will be denied this basic right to timely treatment.

The definition of "treatment" in Bill 109 is too broad. It is so wide that it would include any physical interventions with the patient. As written, the legislation would prohibit even routine procedures such as the application of a dressing or even taking a temperature. We have identified several reasons why delay to treatment will occur. These are as follows:

**The right to an advocate and a board hearing:** If the medical situation is not a clear-cut emergency as defined in the act and the patient exercises the rights set out in the act, most particularly those set out in section 10, treatment of any kind will have to be deferred.

**No treatment without consent:** If the medical situation is not a clear-cut emergency as defined in the act, and a substitute decider is not immediately available to consent to the treatment, treatment of any kind will have to be delayed. Establishing who the appropriate decider is in each particular situation and searching for any appropriate supporting documents will cause delay. Treatment will be delayed in emergency situations. In an emergency situation, delays will occur when health practitioners must determine whether the incompetent person has expressed wishes to refuse the particular emergency treatment or has instructions in a power of attorney for personal care to refuse the emergency treatment.

This legislation will also apply to the community setting. For example, if a health care practitioner visits a patient at home in the country and finds the patient is incapable with respect to consenting to treatment, all of the requirements

of the legislation will have to be observed. The only difference is that the delays may be longer.

It is our understanding that the public trustee has estimated that to serve even 25% of the number of people who may need assistance, his clientele would jump to 150,000 people, which is an 800% increase. He further suggests that his budget would have to be increased from \$6 million to \$48 million. This is but one of the cost implications involved in implementing the legislation.

The public guardian and trustee must have the ability to process cases expeditiously. Although the ad hoc group does not believe it is the best solution, the legislation as written will necessitate that the office of the public trustee be given a mandate which includes 24-hour, seven-days-per-week availability.

The criteria related to emergency treatment are unrealistic. For example, the proposed act permits a health practitioner to administer emergency treatment to an incompetent person only if "the person is likely to suffer serious bodily harm within 12 hours." What if the harm results in 13 hours?

The ad hoc group has concerns regarding linkage between the Advocacy Act and the other two pieces of legislation. Of particular concern is the possibility that the requirements imposed by the legislation will overwhelm advocates' time and impede their ability to address more critical issues. Advocates must have the necessary time and resources to address the needs of those who are most vulnerable. The group believes very strongly that it is extremely important for the Advocacy Commission, as a public entity, to have clear public accountability. The powers, responsibilities, qualifications and accountability of individual advocates require clarification.

Please consider what will happen from a practical point of view if this legislation passes. Some health care providers may endeavour to follow it, refusing to give treatment until they are satisfied all the provisions of the legislation have been followed. Others may ignore it due to its complexity or because they are unwilling to delay all forms of treatment while the technical requirements of the legislation are determined and then followed. Some may be immobilized by its complexity. The end result is going to be a tremendous confusion, especially for the patient.

Given today's fiscal realities, this government would be bordering on irresponsibility to push this legislation through without a cost analysis of its impact on the public, government, providers and institutions. Any initiative must be accompanied by a budget. The government has been asked for a full cost analysis and none has been forthcoming.

We conclude by restating that everyone here today is commenting on bills which apparently have been amended. In its present form, the legislation is potentially dangerous, unmanageable and unworkable. It must be redrafted and rethought.

Thank you very much. We would be pleased to answer any questions you have.

**Mrs Sullivan:** I appreciate the efforts of this group to come before the committee, first of all, but also to work in a consultative manner with one and another of the organizations represented here.

You may recall that close to the end of the last government, there was a document that described the elements, the principles, of consent legislation, and that document was sent out for public discussion. When the government changed, the next action of course was the appearance of these bills in bills.

You have indicated that you feel the consultative process relating to the development of these pieces of legislation was flawed. Could you describe for the record what kind of consultation you have actually had with the government relating to these three pieces of legislation and the interrelationship between the three pieces of legislation?

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**Ms Shushelski:** Each individual group may have had a different form of consultation. My understanding is that these three pieces of legislation, as we see them—first reading and second reading bills—were indeed the first indication of the draft legislation we had seen. Prior to that, the Ministry of Health had actually sent out a document that related to the various principles, which we did respond to. I think most of the groups had the opportunity to give comments on that.

Prior to that, the only other consultation I am aware of is the Fram committee. If you recall that many years ago, it certainly did not have full representation from all the groups at this table. I believe the Ontario Hospital Association and the Ontario Medical Association were the only two on that group. Certainly there was not necessarily a consensus on all issues. That is from my perspective, but I think June Beeby from the Ontario Friends of Schizophrenics may want to address that issue.

**Mrs Beeby:** I can say that Ontario Friends of Schizophrenics has never had the opportunity to sit on any committee dealing with the laws, yet we are the primary care givers of some of Ontario's most vulnerable citizens, severely disabled schizophrenics. We asked but were not allowed to sit on the Weisstub committee. We were allowed to present a brief and we felt our brief was given short shrift. We felt they did not understand it, if they read it. We also were not represented on the Fram committee.

We heard nothing about the advocacy laws being written and were quite shocked to suddenly find ourselves with the acts in second reading. We felt like we had a gun to our head, and we had an empty gun, because we have no legal resources. It is only thanks to the Ontario Trillium Foundation that we were able to respond at all. We were completely ignored by any of the committees planning legislation that would affect some of Ontario's most vulnerable citizens, severely ill schizophrenics.

**Mr Poirier:** Looking at some of the comments, I guess you know by now that we are very sympathetic to your concerns. One of the points you raise on page 2 is, "We understand that the government has drafted amendments to the legislation." I remember, at the beginning of our committee work, I asked that question of the parliamentary assistant. We were answered no, but now that we have had a two-week break, can we ask the parliamentary assistant again what kind of progress has been made by the government to address amendments—if I can get the par-

liamentary assistant's attention. I would like to ask him again, since we had a two-week break, to get some information about whether amendments have been drafted, or if there are addenda to have some amendments come forward so that these groups who have been on the outside, according to what you have just heard, can participate in looking at the amendments, or what you plan to do with the laws.

**Mr Wessenger:** I think it was made clear by the minister when she spoke to this committee the areas she felt should be flagged for considered amendments. One of the areas was emergency situations. I think those areas were well flagged. Since that time, of course, officials in the ministry have been doing consultations with various groups, discussing with them the general principles of the legislation. As of yet there have been no specific amendments set out; we are still in this hearing process. The whole process of this hearing is to hear from groups and hear their concerns. When we have heard from all groups, then the committee process can continue to work and the appropriate amendments will be prepared after we have heard from all groups.

I think it is fair to say that the existing legislation is not cast in stone. The minister has indicated she will be looking for the input to determine the appropriate amendments to come forward.

**Mrs Sullivan:** We heard from the parliamentary assistant to the Minister of Health that there will be amendments to one of the three health bills that are put forward and that we are discussing. There are two other interrelated pieces of legislation. These groups have indicated to us that indeed they believe, and I concur with them, that the only way to proceed is to withdraw these bills and redraft them, because they are unworkable, impractical and costly in their current form.

I wonder if we can have an indication from the government members that the government also believes this is an appropriate thing to do, given that not only this group of organizations that have come before us in a consultative manner to describe what their experience is and what their projections of the effect of these combined legislations would be, but many other groups have come forward saying exactly the same thing: Whether they are advocacy groups, health care providers, family care givers or agencies in a community, every single organization has singular and difficult problems with this series of legislation.

What we would like to see and what these groups and many others would like to see is that this forum be used as part of the public consultation and that it go back into a complete redraft to come up with needed and workable legislation. Can we have any kind of assurance that this kind of approach would be taken by the government?

**The Chair:** Does anybody choose to respond?

**Mr Malkowski:** I would like to reply to that comment. We are in the consultation process now. What we are doing is listening to groups. This consultation has been happening for many years. Consumer groups have been consulted and other groups have been consulted as well. We have heard from three different governments. The Liberal government, the Progressive Conservative government

and the NDP government all say they support in principle that these bills be drafted.

We have heard from the Ontario Psychiatric Survivors' Alliance, from the Ontario Advocacy Coalition and from other groups saying that this legislation should go through. I think we need to be fair to all groups. They have concerns and that is why we are here: to hear the concerns and consult with the groups.

**Mrs Sullivan:** Will you withdraw this legislation and go into a redraft?

**Mr Malkowski:** We are going to continue to consult and continue to listen. When the public hearings are finished, we will discuss and talk very directly about making amendments. Just for clarification, we will make recommendations after the discussion is finished.

**Mr Winner:** I would like to speak in connection with Bill 108. We too have listened very carefully to the helpful, positive, constructive suggestions made by the many deputations and we are going to consider carefully how those contributions might make our legislation better, but not until we have heard from everyone.

**Mr Sterling:** I would like to thank the coalition group for stating at this point in time its concern particularly about the process. One of my concerns is that we have had a lack of presence of ministers in this committee who are responsible for the legislation since they made their opening statement. While parliamentary assistants can assist ministers, it is still the minister who must make those decisions. We have not seen the Minister of Citizenship here, we have not seen the Minister of Health here and we have not seen the Attorney General here to listen to any of the suggestions that have been made. I would suggest that this legislation is being considered in a considerable vacuum on the government's side at this time and that concerns me. It concerns me when I couple it with the lack of media coverage of these hearings, for whatever other reasons there might be, because there are other issues that are more interesting to the public.

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The third part that I am very much concerned about is the leadership in carrying this legislation being put in the hands of the Minister of Citizenship. Quite frankly, this legislation impinges more on the health care system than any other ministry in this government, and it is my view that the Minister of Health should have been the lead minister with regard to this legislation because that is where the practical effect of this legislation really lies.

You may know that my party has put forward amendments. I hope you have received those amendments from the clerk of this committee, as was agreed in this committee before. After two days of hearings, we put forward—

**Mrs Beeby:** We have not received them.

**Mr Sterling:** You have not received them? I will ask the clerk later why you have not received those amendments. We have put forward three amendments to this bill because we saw an immediate problem with regard to those parts.

One of the problems I have—and I have heard rumours that the government is considering scrapping Bills 108, 109

and 110 and proceeding with Bill 74—is that the government is getting the impression that there is little opposition to Bill 74 at this time, and I would like any of you to comment with regard to Bill 74. I know it is entwined with Bills 108 and 109, but it seems that everyone gets tied up in specifying the problem with Bill 108 and 109, without referring to Bill 74.

**Ms LeBlanc:** Actually, I think that is a big problem, and if you look back to the consultation, it really is Bill 74 that sprang from nowhere, if you will. There was a discussion paper on principles respecting consent and there was the Fram commission, so there was at least some background. Bill 74, which is ostensibly the centrepiece, has had no preliminary information, and that has made it doubly difficult. I think one of the things we as a coalition have come to realize is that this has been put forth as a package and it should fall as a package.

**Mr Sterling:** Can I ask a supplementary question? I am sorry, Jim. In listening to this and in dealing with Bills 108 and 109, most of the criticism seems to fall around three or four or maybe half a dozen sections of those bills: the assessments in Bill 108, who can do an assessment, the complexity of doing an assessment, what is a valid directive, what is not; the definition of treatment in Bill 109, whether diagnostic treatment should or should not be included; the section about the age of the young people.

In trying to continue to be constructive, from our party's point of view, we are reluctant to let these bills go. Notwithstanding the considerable number of problems we see with them, if those six or eight or a dozen sections were remedied or if there were constructive amendments put forward by the government, do you think that after adequate consultation, following that, the health care community could work to try to make this legislation go ahead?

**Ms LeBlanc:** That is, I think, the hope of all of us.

**Ms Shushelski:** Perhaps I could just make one comment on that as well. What we hope is that whatever amendments are proposed or whether the bills are withdrawn, whatever form it takes, the one aspect I think we all agree on is that we need the time to consider it. I think this legislation is going to have such an impact on health care for Ontario, and for such a long time, that we have to make sure it is correct. We all have to live with it permanently. What I suggest is that what we could all agree on is that we need an adequate consultation period to determine what the amendments are, to make sure they are workable.

**Mr J. Wilson:** Thank you very much for appearing today. Although I never want to try to outdo Mrs Sullivan, if you read the debates in the House on second reading, as Health critic I certainly made it clear at that time that we felt the bills should have been withdrawn and in fact redrafted. It is nice to see the Liberals are with us here this morning to reaffirm that.

Subsequent to that though, what Mr Sterling is getting at is that he has managed to convince me somewhat that perhaps we could, with some substantial amendments to Bills 108 and 109, eventually live with that legislation if we could get the government to listen and withdraw Bill 74. As Mr Sterling has also pointed out, the government is

going in the exact opposite direction to what our thinking is and to what I believe the vast majority of witnesses before this committee have told us. On that I want to ask you a question, just as a group that has taken the time out to come to this committee.

From your presentation I think you would agree that if the government has amendments hidden away somewhere, it should have brought them forward by now. Do you feel it is a waste of your time to come here and debate matters that the government says it has already got in the workshop, fixed, but will not release out of the workshop to let us know? This government, in all committees, seems to think this is where it does its public consultation rather than prior to drafting the legislation. We have spent some 18 months now trying to tell them how Parliament best works. Do you feel it is a waste of your time and that you are not being heard? It is a pretty tough question.

**Ms LeBlanc:** I think it is fair to say.

**Ms Shushelski:** I think the group would agree that we feel we are wasting time. We could give far better information to you if we had the most recent thinking. Certainly this would appear to be a waste of time.

**Mr J. Wilson:** Thank you. I just wanted to clarify that, because it would be interesting to hear what the parliamentary assistants tell us in that regard on the amendments.

**The Chair:** I remind the government side that you have about seven minutes. I have had four people indicate they would like to ask questions. Mr Malkowski.

**Mr Malkowski:** I would be interested in your clarification. In your submission on page 4 when you are talking about the powers, qualifications and accountability of the individual advocates, I would like to hear some clarification on that point. Do you have any specific recommendations where you could see improvement?

**Ms Wolman:** I will just speak briefly, but not totally on that issue. Representing a group of 25,000 frail seniors, but not all of them physically challenged and certainly not all of them mentally incapable at this point in time, although some of them may be in a very frail position, the composition of people that is being recommended for the Advocacy Commission in my view would not necessarily be knowledgeable enough or familiar enough with the needs of our frail elderly population to be able to deal with them in a certain situation.

In addition, if we read the bills the way they are presently worded, with 500 retirement homes across this province, in order to have ready access to an advocate if needed, if the legislation is followed to the letter, the way it is presently written we would have to have a permanent onsite advocate in every retirement home. We would have to have an onsite person there 24 hours a day to protect the people living there, with whose care we have been entrusted. We have a lot of concerns about both the cumbersome way that would evolve, the cost, and the fact that the advocates may not be trained in the areas in which they are needed because the act is so broad.

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**Mr Malkowski:** In principle, the Advocacy Act is to protect vulnerable people from abuse, neglect and exploitation. Would you support that principle?

**Ms Wall-Armstrong:** That has been reiterated many times. There is no question that we all support the basic principle, but we all recognize that what is being forwarded may be more cumbersome than what we are working with right now.

**Ms Shushelski:** Jean Suttie from the Victorian Order of Nurses would just like to comment. She got bypassed.

**Mrs Suttie:** I would just like to comment from the perspective of VON. As many of you may know, we have about 4,000 staff working across the province on a daily basis, and cover over 90% of the population. However, we are not contained in a facility. We are very much out on the back roads of the communities and often run into some difficulties vis-à-vis the availability of assistance. We need some clarification and some thought given to the availability of the advocate if this legislation is going to go forward. From our perspective, we would like to see some consideration given to the community in general because we do have a lot of uncontrolled variables which are very costly to us, both from a human resource and a financial perspective.

**Mr Fletcher:** Just two quick questions. A lot of people have been coming and saying, "We like the bills, some of them, but we should perhaps implement the Advocacy Act first, let it run for a couple of years, get it going and see what bugs there are, and then start implementing the other pieces of legislation." As I said, this is coming from other groups. I was just wondering if there is anyone who has thought about that. Or is it just a total rewrite of everything?

**Ms Wall-Armstrong:** I think the concern has been that this was presented as a package. It is difficult for us to separate each one of them. I know our organization and the Ontario Nursing Home Association have said, "Whatever you're going to be implementing, in doing so, we do need an opportunity." One of our suggestions was a pilot project on it, because if any of it is implemented province-wide, we anticipate there is going to be some difficulties with it.

I think many people sitting up here in this group are saying, "We all need an opportunity to work out our own kinks, and no matter whether you're going to bring forward the whole package or just part of it, you're going to need a pilot project so that we can all assess the impacts on it." But we have been presented with it as a package. For us to try to take it back—it has been so interrelated. Our focus has been as a package. If you want us to look at them individually, then let us know and we can get back to you on that and see if that is workable.

**Mr Fletcher:** The other point is that you say you have heard about the government making amendments already. Where did you get that information? Where did you get this idea that we have made amendments?

**Ms LeBlanc:** Certainly we have had discussions with a number of different sources and, as Mr Sterling mentioned, Frances Lankin has been fairly forthcoming in saying

that she is prepared to at least put forth amendments where needed, and I think some of the staff people have certainly made it clear that they are working towards amendments now.

**Mr Fletcher:** That the minister would say that she is clearly willing to put forth amendments means she has already made amendments?

**Ms LeBlanc:** From some of the staff people in the ministries, we have learned that amendments at least are under way.

**Mr Winner:** I do not want you to go away misled by Mr Sterling's reference to a rumour that Bills 108, 109 and 110 are being withdrawn. I think that is a rumour circulating among the Tory caucus members. But there is more truth to the rumour that Mr Sterling has withdrawn Bills 7 and 8. I would also say that ministries can recant. The members of the opposition well know that. The ministers read Hansard. The parliamentary assistants are here on the committee to bring back your thoughtful suggestions to the ministers.

We also have competent counsel, Mr Fram, sitting behind me and other counsel for the other two ministries involved, all of whom are listening very carefully to your suggestions. My question is, do you not think that the advance medical directives and the powers of attorney for personal care will actually help to facilitate the kind of treatment the patients want, rather than operating in the current vacuum, if you will, where health care practitioners conclude often they have consent to treat when they do not?

**Ms Wall-Armstrong:** If you could be assured that the public would be well educated before coming in and that its use would be widespread, but usually what happens, from a practical concern, is that the public is not aware enough about these pieces of legislation, and it is only getting dealt with at a point in time when people are in a deteriorated health condition. Those are our concerns, and when it gets to that and it is not an emergency situation, we can deal with it where we have got a terminally ill patient who is not cognizant, and it takes four or five months to be able to give them proper, adequate palliative care. I would like to see those things change, but at the same time I do not want to scare off even the people working in our environment right now by new legislation coming in. They are used to the environment they are working in.

**Mr Winner:** I will give my remaining time to my colleague.

**The Chair:** There is no remaining time. On behalf of the committee I would like to thank your ad hoc committee for coming and giving your presentation this morning.

**Mr Sterling:** When I introduced our three amendments some three weeks ago, I had asked the Chair to forward those to all of the groups that had presented and were going to present so that when groups came in front of the committee, they would have the position of our party at that particular time. I would just ask if that has been done, because there was some negative response when I was making that statement.

**The Chair:** I will allow the clerk to respond to that.

**Clerk of the Committee:** My understanding was that they were to be provided to all groups, and they were provided to all groups prior to their presentations. I just sent a memo to my office now that they are to be faxed to the remaining groups this week for their presentations.

**The Chair:** To allow time to arrange the seating for our next presenter, this committee stands recessed for about two minutes.

The committee recessed at 1108.

1117

#### BURLINGTON COMMITTEE FOR THE PHYSICALLY DISABLED

**The Chair:** I call this committee back to order. Our next presenter is from the Burlington Committee for the Physically Disabled. Good morning. As you know, you will be allowed half an hour for your presentation. The committee would appreciate it if you keep your comments to about 15 minutes to allow time for questions and comments from each caucus. Could you please identify yourself for the record and then proceed.

**Mrs Marsden:** My name is Anne Marsden and I am chairman of the Burlington Committee for the Physically Disabled. Before I begin, I would just like to give a brief rundown of the adventure I have had trying to get in here this morning, which I think will be an excellent analogy of Mr Jim Wilson's comments during the last presentation.

Before I set off, by the way, I should introduce my son, Dale Marsden. He is job-shadowing today—the day in the life of an advocate—and he will be reporting back to his school.

This morning I received a call from Marilyn Heintz, president of People First, who has accompanied me here today, to say that we were going to have a little bit of difficulty getting here because Queen's Park was surrounded by trucks and they were not letting anyone in. We took a detour and came by Highway 5. As we approached the trucks I held up my disabled pass and the trucks kindly welcomed me with a blast from their horns and opened up so we could come through.

Then we were met by the person who is an employee of this government, I presume, whose job is to keep undesirables out of Queen's Park. He stepped in front of my van and said, "No, you can't come in." So I said: "Why not? I have a disabled parking permit, I have been told there is disabled parking right outside the front door and I have an appointment before the administration of justice committee. They have invited me here to speak on Bill 74." He said, "No, you can't come in, there's no parking." So I said, "Excuse me sir," and then I did what I am always used to doing, I drove right through the barrier. He came running after me. There were barriers up in the handicapped parking spot and my son, who tends to be useful at times, went out and removed the cones from the handicapped parking spot. Along comes the government employee meant to keep the undesirables out of Queen's Park, "You can't park there." I said: "Excuse me, sir, I have a disabled parking permit. I can park there."

I think that is a perfect analogy of what you were saying, Mr Wilson, that on one word you say, "Please come. We are doing everything to make equal access for the disabled," but you just try and get here and you see how many barriers are going to be put in your place. But as I said, I do not let barriers stop me so I am here today. I am going to be speaking from the heart because I did not prepare anything on purpose so you know it is from the heart, and I am going to be drinking lots of water.

First of all, I should let you know why I feel I have some credibility to sit before you today and speak on this bill. I was born in England, a very healthy baby girl, walked at nine months, very happy little girl. At four years of age I received a diphtheria, polio and tetanus immunization. From that day on, it was a different story. During my youth, I had 13 lots of major surgery so I am well aware of why we need advocates within hospitals, as a child. I went to an able school. I became the school tennis champion. I was the only disabled person in that school. At 13 I threw away my braces because I no longer liked them. They were ugly.

During that time my mother was diagnosed paranoid schizophrenic. She was sent to the local asylum. During that 10-year period she received at least 100 electric treatments. She also received several of the insulin coma treatments. My mother, bless her heart, has survived. She is now in Halton Centennial Manor, where recently I noticed a change in my mom's behaviour. I could not understand what was happening and found out her medication had been mixed up. Instead of the medication she was supposed to be on, an antihallucinatory drug, they had given her a diabetic medication. Now you know why we need advocates within the nursing homes.

These last four years I worked for a hospital. I have been very active in patients' rights, a member of the patient relations committee. The last four years, up to January 1991, I went through the most distressing and horrendous obstruction and harassment to put me on long-term disability that you could ever come across, and it is all documented.

In January 1991 I succumbed to the pressure and went on long-term disability, served a formal Ontario human rights complaint and also put forward a Workers' Compensation Board claim for occupational stress, well evidenced. My experience within the hospital shows me why we need advocates within our hospitals for patients. I myself worked in an office which underwent \$100,000 worth of renovations including new carpets, new pots, silk plants, the lot. When I went to the Chedoke site of this same hospital I was not even allowed access up the stairs, nor were the patients who were in that chronic care and rehab centre. They did not have an elevator. I tried unsuccessfully to change that. They would not even accept me as a part of the consultation process.

When it was brought to people's attention: "That's life. There's no money for elevators." I said, "What about the money for the \$100,000 renovation to the new office I've just sat in?" Now you know why people with disabilities need advocates so we can move the barriers. As you can see, I am very much in favour of there being advocacy. My

problem comes, however, with the experiences I have gone through over the last year.

Oh, sorry. I missed one other case where I have used advocacy services. During this last summer, my child went into severe emotional trauma and out of control. We could not understand what was happening. We knew it was probably something to do with the anxiety that was going on in the home. His mom was not her normal self. She was not going to work. She was getting all these phone calls. She was concerned that we would be losing our house because she no longer was able to provide 50% of the income.

We had many difficulties with him. We tried to go and find mental health resources to help this child, because nobody could. Our family doctor says we cannot. The children's assessment and treatment centre, which is our local mental health centre for children, says no, that we cannot even put him on the waiting list; it will be 10 months. This child was in extreme difficulty. One day he went totally out of control. We did not know what to do with him. We tried to get family support, anything that would help us understand what was happening to this beautiful child, which he is.

One day I called my family physician and I said: "He's totally out of control. What can we do?" He said, "Do you want me to call the children's aid?" So I said, "Why would we call the children's aid?" He said, "Because the children's aid will find the necessary medical help that Jason needs." So I said, "Fine, call the children's aid."

Children's aid came and took my son. They told me it did not matter what I wanted or what my doctor said; they held the power and they were taking my son. This was in response to a call for help to deal with a child's problems. I was left powerless. If you know what it is like to sit in a living room and watch your son being walked out, you know what it feels like to be absolutely powerless and in the grips of a piece of legislation.

I was put in touch with the child and family advocacy people. What happened was that the worker came down and told us that if we did not want to go before a court, where our son would be kept for a minimum of three months, we would have to sign a temporary order putting him in the custody of the children's aid. We would have to sign it. We debated it. We were very frightened. So we signed an informed consent to put our child in the children's aid.

The home he went to had 11 children in it. We called the children's aid. We said, "How can my son get the attention he needs in a home with 11 children in it, especially when, from what we understand from the children's aid, they are all people with major behavioural problems?" They said: "No, it can't be so. It's against the law. Can't have more than five." I said, "We are telling you there are 11 children in there." "No, no, no."

She checks it out and comes back to me. "Yes, well, she's only got five foster children, but she's got six respite children, too, severely disabled children who go there." I said: "You mean 11 children, six of them with severe disabilities, looked after in one foster home? What kind of attention is this child of mine getting who is in severe

emotional difficulties?" She says: "Don't worry about it. It's okay. Everything is under control."

My son then informed me that he was sharing a bedroom with a girl. I said, "Impossible." I phoned the children's aid. "Absolutely impossible. It's illegal to share a room with a girl." That night my son was moved from his bedroom to another room to share a room with a boy. I think you can get the picture of why we need advocacy within foster homes.

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I also had called the foster mother to let her know my son was hypoglycaemic and that this was thought to be one of the causes of his problems, because when his blood sugar drops he does not know what is happening to his body. The week he was taken by children's aid we found he had eaten a full tub of Betty Crocker icing sugar. We only found that out because it was downstairs and it was my other son's birthday and we went to ice his cake and it was gone. We asked Jason. He had eaten a full tub of Betty Crocker icing sugar, which to us accounted for his out-of-control behaviour.

I phoned the foster mother and I said: "My child is hypoglycaemic. Can you please ensure he gets a snack midmorning and midafternoon and that he goes to school with his lunch and that he has sufficient to have a morning snack, a good meal at lunchtime and an afternoon snack, and no sugar." My son went to school the first day with one sandwich and a package of Lifesavers. My son got into extreme difficulties and was again suspended by the principal. My son was suspended by that school three times in three months.

The principal was talked to by my doctor, who told her he was hypoglycaemic. He told her not to confront him in a confrontational manner. He told her that in no way should he be grabbed or anything like that because he had been traumatized by an adult. She grabbed him by the arm. He responded by kicking her because he felt he was in danger, and he was suspended the third time. He ended up suicidal at that time on my roof. You now have an indication why we need advocates within the school board system too.

We wanted to move my son over to another home, some people from our church who were cleared as foster parents. They had no children in their home. For three days we had to beg—the legislation provides for this—that they move our child over to this other home. No, they would not move our child over. We called the child advocacy people. The children's aid told us there was no way it would listen to the child advocacy people; it had the power, even though it is in our legislation and it is our right to move our child over.

They would not even let me tell my son there was somebody else who wanted him. We explained that his self-esteem is so low and we would just like to show that this family really wants Jason. We said, "Can we please tell him that the Teklenburgs want to have him in their home even though they know him and they have heard all about his behaviour etc?" The children's aid said no. We were not allowed to tell our son that somebody else wanted him.

Finally, after three days, they released my son to another home. We then finally got an appointment with a child psychiatrist, which was supposed to be the purpose of children's aid taking him in the first place. On the advice of this psychiatrist, they released him back to our home. At this point I went out to the community and fought very hard to get funds for a family support worker to work with our family to show us how to deal with our son when he went out of control and for a behavioural therapist to help Jason. By the way, I should say that when I went forward to this committee the children's aid came against us and recommended that we not have them.

The local mental health association, if that is what you want to call it, the children's assessment and treatment centre, told us that all children's aid had to do the day my son was taken into care was call it and it would have my son as an appointment within the first month. The children's aid knew this; it did not make the call.

Finally we got this family support worker. In April my son was taken; August was the first appointment with the family support worker. The family support worker came into my home and said "Hi," introduced herself, and then said, "I don't understand this," because she was under contract to CAS. She said: "I don't normally come into homes after children have been taken into care. My job is to come into homes and support the family before the child is taken into care." She said, "I'm normally paid through children's aid." So I said: "Well, can you answer me why, instead of taking my son, a family support worker was not provided by children's aid? It would have been far cheaper, it would have been far less traumatic on our family, and the legislation says the purpose of the children's aid is to keep families together."

I think you may well have got the point as to what I am talking about in terms of legislation advocacy, what is supposed to happen and what does not happen. I have many, many examples which I would rather share with you in private, if you so wish, of how our legislation has been utilized expressly opposite to the way it was intended to be used. Many examples. As I said, I would be delighted to share these with you in private.

Before you send Bill 74 or any piece of legislation on, I think you need to take a retrospective look. I should tell you that my professional background is quality assurance. In quality assurance you undertake studies to look at the problem. The study identifies what the problems are in order to be able to make recommendations to fix the identified problems. After you have ensured the recommendations have been put in place exactly as they were supposed to be put in place, you then reaudit, take another look, and see if the recommendations had any impact at all in changing the behaviour of the people involved or the situations involved. That is how you resolve problems. That is the end of the complete circle.

What I am saying today is that we have some problems with our legislation in this province. I do not particularly think the problems are within the legislation. I think the problems are with the people who believe they can thumb their noses at that legislation. That is very well shown to be correct. As I say, I can share privately with you exactly

where these people have managed to thumb their noses at legislation and continue to do so. Thank you.

**Mrs Sullivan:** Thank you very much, Mrs Marsden. In your exposition of your personal and family association with schools, hospitals, medical care and so on you have indicated that you have dealt with many agencies in our own community, one of which was CATC, which, for Hansard, is the children's assessment and treatment centre. It is really a very fine agency. But as you have documented your experiences, you have given evidence that you see a particular role for advocates in relationship to schools, to hospitals, to nursing homes, the children's aid society, various social agencies in the community, health care, including a review of medical practice and in fact medical treatment.

What I hear you saying is that there is a requirement for a scope for a bureaucratic approach to advocacy, and I wonder where you would see the limits or the extent of the scope for advocacy, the kinds of training requirements that would have to be put in place on a publicly funded basis, and the funding needs to support the kind of broad-based advocacy services you are talking about.

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**Mrs Marsden:** I do not think I am talking about broad-based advocacy services. What I am talking about is making these agencies accountable. I do not believe setting up another commission along the same road as the Ontario Human Rights Commission is worth anything. It is just throwing another how many millions of dollars down the road. I do not believe that setting up an Advocacy Commission is the way to go. You have tried it in the past and it has failed miserably.

**Mrs Sullivan:** So what you are saying is that the role and the services provided within agencies, at the checkpoint role, should be expanded within the existing institutions and that in fact there is no need for a new bureaucracy.

**Mrs Marsden:** Exactly.

**Mrs Sullivan:** You see existing social and health care services expanded to take care of that advocacy requirement and to provide a protection for patient and consumer rights.

**Mrs Marsden:** I think, if there is accountability, you will find the dollar expenditure going down. For instance, my son, Jason, was sent by his doctor for a test for hypoglycaemia, a blood sugar test. If it had been carried out 18 months previous we would have avoided thousands of dollars worth of health and social services expenditures. He asked for this test after I had gone to him and said: "We see a relationship with Jason's anxiety, his craving for sugar and then his behaviour. Is there any kind of research which shows that?" I know I had suffered from chronic fatigue as one of the stress symptoms, and the research I did on that showed that stress caused me to burn up my sugar, and we know that sugar feeds energy.

I said, "Is there anything to do with the anxiety level, the requirement for sugar that the body is crying out for and his behaviour when the blood sugar drops?" He pooh-poohed that idea, but nevertheless, on a psychologist's request, he was sent for blood sugar testing. The doctor called me on Friday evening and he said, "I have never

seen a blood sugar drop so quickly and so low in the space of one hour." He said one hour after my son eats sugar he is in extreme difficulties. So I said, "What do we do about this?" He said there is no cure and no treatment. It is controlled by diet.

He is talking to the paediatrician we talked to the week before. This paediatrician said, "Absolutely not." He said that now he was able to show him the test results and the paediatrician was now going out to research the literature to see what the connection was. My response to him was: "Isn't this interesting? Do you know how many community resources have been spent? A family support worker for the Marsdens, a behaviour therapist for my son, two and a half weeks in children's aid and I don't know how many appointments with the doctor." If there had been appropriate recognition of what my son's problem was there would be no need for any of that expenditure of those health care services or those social service dollars. This is what I am saying.

This is what quality assurance is: You identify where your problems are. I believe your problems are within the system. Having had 17 years in hospital management—right now I know Gary Carr in a report said our health care costs \$17 billion in Ontario. I can tell you from personal experience that health care does not cost \$17 billion in Ontario. We give our hospitals \$17 billion. What I am talking about is accountability to ensure that money is spent on health care needs.

**Mr J. Wilson:** Yours is a very interesting presentation because you took us through the need for advocacy services, but as I understand, although you identify needs in various systems—the school system, children's aid and the medical-hospital setting—you would not be in favour of setting up another bureaucracy, and that is a very interesting perspective. I think you were here for part of the coalitions, the OMA and nurses, that appeared preceding yourself. They talked also a little bit about how the family in this legislation could be somewhat ignored or certainly is down the list to be called in later, after the advocate. Have you given some thought to that? You talk about current legislation. Particularly I agree with you on children's aid; it is supposed to keep the family together, and it is not followed. This one, in my reading, specifically excludes the family.

**Mrs Marsden:** That is my point. There is legislation out which says the purpose of the child and family legislation is to keep a child in the family. Children's aid took my child out of the family when it was absolutely unnecessary at the cost to this province of community and social services dollars. What I am saying is, you can write whatever you like on that; it does not make a difference. The people who are in the hospitals, the people who are in the children's aid, the people who are in this government will do what they like. It is exactly the same as employment equity: \$158 million to this country to integrate the disabled people. I try to come in response to an invitation and what happens? "You can't come in here. You can't park there." That is exactly the point.

**Mr J. Wilson:** I think you are a tremendous advocate, and your son should be very proud.

**Mr Carr:** I just wanted again to thank you for coming. I know we have spent some time. I saw Marilyn in the background there from People First. As a matter of fact, I was reading some of the replies on this bill from the people, and Marilyn will know we spent some time. She sits on one of my advisory committees, and we have gone through it. I just got the summary that we are going to circulate to our people, and I want to thank you very much for coming in and presenting that. I guess we will get a chance to get together afterwards as well.

It seems like the government has said it is prepared to go forward with this particular piece of legislation. I was wondering, with regard to Bill 74, if you would like to see something similar to a smaller-scale pilot project first, rather than proceeding. Knowing that the government has said it is going to proceed, and I think that is a given, are there any other recommendations you could make? I know you talked about how people could thumb their noses, but specifically is there anything else you would like to see incorporated?

**Mrs Marsden:** Talking about pilot projects, I would just like to give another illustration from our own community. This government has gone on record in the Legislature to say it supports long-term care. Part of those long-term care proposals are local community centres.

I do not know whether you are aware or not, but I did send a letter to Mr Cam Jackson asking him to raise it in the Legislature, so I assume you are aware of it. The purpose of the letter was to say our government is saying, "We are going towards long-term care, we are going towards community health centres." One in Burlington, at which I was a patient for a year and had every opportunity to evaluate, is a very cost effective centre doing wonderful work, the Joseph Brant health centre. What happens? The government comes up short with the executive director's wish list, if that is what you like, in funding for his hospital this year. What does the executive director do? He closes. He has said that that centre will close at the end of June.

My question to Mr Jackson to put to you people in the Legislature was, how can you allow a hospital to thumb its nose at you in terms of saying, "We are going to long-term care"? How can you allow a hospital to hold a community up for emotional blackmail? Because that community centre's closure does not just affect those patients in there. It affects me, it affects every single citizen and his or her tax dollar, because it is going to cost a fortune in health care dollars and community social services dollars to replace that \$500,000 expense.

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What I am saying is, pilot project or not, it does not matter. If Joseph Brant closes down, that fine example, contrary to what you people have said is going to happen, what is the point of pilot projects? It is accountability in terms of what we have, what the laws of this land are, and making people accountable, and morally accountable as well as accountable according to the legislation.

**Ms Carter:** Thank you for coming and telling us your very moving story. I am really sorry about the parking problem. We will certainly have to look into that. You did not need that.

**Mrs Marsden:** I am used to it.

**Ms Carter:** Maybe Bill 74 comes a little nearer than you think to doing what you would like. Obviously, what we need is something that is independent of government, that is arm's-length, that can criticize the delivery of services. Somebody this morning was querying why it should be the Ministry of Citizenship and I think that is why, because that is the ministry that is concerned about people, people's rights, disadvantaged people and so on. This is a very consumer oriented bill. This is to help people.

There are two parts to it. The commission will listen to individuals, find out what they want and act on their behalf, but there also is another aspect, and that is systemic advocacy. In other words, if they find out that there is a whole class of similar problems occurring, that people are running into the same types of difficulty, they will say, "Well, there is a problem with this institution, or this way we do things" and they are empowered to do something about that and change the system. So the overlooking of institutions, seeing how they function, monitoring from the point of view of the consumer, that is part of what we are hoping to achieve with this act.

Of course, the one place where we do have advocates in place under the government now is the 10 provincial psychiatric institutions. I believe that this is something that has happened. First of all, they have been able to alert the families of inmates who are not being treated as they should be. Maybe the families are at some distance and they are able to come and find out and intervene. They have also helped by simply being there, being a watchdog, and fewer abuses have occurred because of their presence. I am just wondering what you thought about that aspect of it.

**Mrs Marsden:** You use the word "empowered."

**Ms Carter:** Yes.

**Mrs Marsden:** I prefer the word "enabled." I am very much empowered, but unless I am able to get into this building, I cannot respond to your request.

I really believe that rather than have another piece of legislation, we need accountability. To build accountability into the system, I think we need the public voice. It is time to open up those boardrooms to the people whom the centres affect. Remember, part of my job is working with the board. I was the board secretary for a hospital board and its committee, so I know how they work. I know who is on the board and why they are on the board. I believe they need to be opened up to the public. I believe the public, whose needs these people are meeting or are supposed to be meeting, are the people who should prioritize where the dollars go and what is a needed service and are the people who should be reviewing in terms of accountability.

This would also be very economical. For instance, in Hamilton there are three hospitals, three boards and three PR departments. Chedoke McMaster Hospitals have a staff of three in the PR department. I cannot figure out how that

is a health care need. They all have foundation offices with their staff all running around in competition with each other and trying to raise funds. It really disturbs me when all I see in the Burlington Post is funds going out to Chedoke McMaster when I know CATC has a 10-month waiting list.

If you put in one regional, publicly appointed board and make it accountable, have an accountability factor in there too and put the proof of accountability in the hands of the people it affects rather than the people who are looking forward to some business from this particular institution, I believe it would be much more economical and that you would get a much clearer picture of what the needs are. I believe that will work far more effectively than a commission.

**The Chair:** Mrs Marsden, on behalf of this committee I would like to offer you the opportunity to submit—

**Mr Fletcher:** They had two each. They had their two.

**The Chair:** The point is that we are on a time limit, Mr Fletcher. Each caucus had five minutes on this.

**Mr Fletcher:** It did not seem like five minutes.

**Mrs Marsden:** Does Mr Fletcher wish to ask me a question?

**Mr Fletcher:** I will ask you one later.

**Mrs Marsden:** I will make sure it is on the record.

**The Chair:** As I was saying, this committee would like to offer you the opportunity to submit a brief if you have more to tell the committee. If you submit it to the clerk, she will distribute it to each of the committee members and they will review it.

As for the blockade this morning, I understand it caused some difficulty. The Sergeant at Arms and security offer their apologies. They will be looking into why an exception was not made on your part. On behalf of this committee, I would like to thank you for coming and giving your presentation this morning.

**Mrs Marsden:** Mr Cooper, I would just like to say I am not looking for exceptions. I was invited to this committee and I was told to park right outside the front door, so I was looking to accepting your invitation.

**The Chair:** The thing is that because of the blockade, there was a mandate sent down that no cars be allowed in. Our apologies again.

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#### ST MICHAEL'S HOSPITAL ETHICS COMMITTEE

**The Chair:** I call forward our next presenter, from the St Michael's Hospital Ethics Committee. Good morning. I remind you that you will be given a half-hour for your presentation. The committee would appreciate if you would keep your remarks to about 15 minutes to allow questions and comments from each of the caucuses. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Dr Wong:** Thank you, Mr Chairperson. I am Dr Gerald Wong.

**Ms Prentice:** I am Linda Prentice.

**Dr Webster:** George Webster.

**Ms Walkerley:** I am Shelley Walkerley.

**Dr Wong:** We represent the ethics committee at St Michael's Hospital. We would like to thank you very much for the opportunity to come and talk to you about these bills. We will be talking about Bills 108 and 109 and Bill 74. The first presenter will be Linda Prentice, the second presenter will be Shelley Walkerley, the third presenter will be George Webster and I will be the last presenter.

**Ms Prentice:** I am the social worker on the ethics committee at St Mike's Hospital and my comments, I would say, reflect much of the discussion we have had in terms of the ethics committee itself.

A main concern about the proposed legislation is focused on Bill 74. In particular, the act seems to suggest that special advocacy services, strangers to the patient and family, best serve the interests and wishes of people who are deemed vulnerable and incapable rather than the family and the health care professionals.

I consider this assumption to be overkill for the vast majority of people, families and attending health care professionals. A particular issue arising will be the amount of bureaucracy to be developed with the accompanying paperwork and costs which will burden the system, which is severely unable to keep up with rising health care expenditures.

In our experience, the existing bureaucracy for dealing with the financial affairs of incompetent patients leaves them often stranded without access to their own financial savings and pension income while in hospital. If this process occurs now, what will be the results and implications of bureaucratic mandatory advocacy services dealing with even more people who are in critical phases of acute illness?

I agree with previous recommendations, which I have read about, made to this committee that such expansionist services be assessed first on a trial basis with research examining the intended and unintended results from these proposals. Again I urge that the good intentions of assisting those vulnerable persons at severe risk not unintentionally compound the issues of the average citizen and his family dealing with the illness such as stroke or head injury in an acute care hospital.

If the legislation intends to correct perceived injustices in the system of health care delivery, would the dollars not be better spent in upgrading, in education of staff to ensure its standards are met?

**Ms Walkerley:** My name is Shelley Walkerley. I am a registered nurse practising in the position of a staff nurse at St Michael's Hospital in Toronto. As part of a group of professionals who are members of the hospital ethics committee of St Michael's, I will present comments and recommendations specific to Bill 74, the Advocacy Act, and Bills 108 and 109.

Since I am a nurse, my assessments and conclusions reflect that perspective. My statement is an expression of my own opinions; however, it reflects the position of the department of nursing of St Michael's.

Nurses are required to provide advocacy services for individuals, families and communities through the Standards of Nursing Practice, the College of Nurses, 1990, and the

Code of Ethics for Nursing, the College of Nurses, 1991. Both these documents reflect nursing's commitment to community involvement in planning and delivery of health care services. That is to say that I, as a person and a nurse, support the principles of advocacy and community participation as stated in Bill 74.

However, I have some areas of concern, specifically, subsections 19(1) and (2), right of entry. Although right of entry to facilities is well explicated, right of access to persons is not. Since my perspective is the general hospital, I will refer to persons in hospital as patients. All patients in a general hospital would fit the definition stated in section 2, ie, "vulnerable persons." The means of an advocate gaining access to patients is not specified. Clarification is required on the following points:

1. Is it assumed that any person fulfilling the specification of subsection 3(2), advocate, is able to provide advocacy services to any person deemed to be vulnerable, or would services be provided based on the advocate's category, as stated in subsection 15(1), and the vulnerable person's illness or disability? For example, would an advocate from the AIDS Committee of Toronto provide services to anyone in need or only to person with AIDS?

2. The mechanism for identification of vulnerable persons is not specified. Having gained entry to the premises, how does the advocate go about determining which patients require services? In present practice, access to patients is granted to health care practitioners and hospital staff through a consultative process. A patient's right to privacy is respected by this process. If advocates have access to all patients, based on an assumption of vulnerability, the right to privacy could be infringed. Universal access could also interfere with the environment of trust that is essential to the provision of care.

If advocates provide services according to their category, as stated in section 15, how are they to determine which patients they should have access to? It would constitute a breach of confidentiality for hospital staff to provide a list of patients based on diagnosis. Personal information cannot be shared without permission of the patient or his or her surrogate. Staff acting in a patient's best interests by obtaining permission for access could be open to fines under section 34 if their action is construed as hindrance or obstruction. Further clarification of the means of access would ensure that health care practitioners and advocates exist in a relationship of collaboration and cooperation in providing advocacy services to persons in need of them.

Security and wellbeing of vulnerable persons: Bill 74 is entitled An Act respecting the Provision of Advocacy Services to Vulnerable Persons. The bulk of the legislation deals with codifying rights and entitlements of advocates as a means of ensuring the provision of service to vulnerable persons. Although clause 7(1)(h) calls for the commission "to acknowledge, encourage and enhance individual, family and community support for the security and wellbeing of vulnerable persons," subsequent sections do not specify a role for families, acquired or biological, or health care providers as agents of advocacy. Additions to the act, recognizing these groups are reliable and trustworthy ad-

vocates, would fully empower all persons to determine their own need for and access to advocacy.

Surrogate relationships: This relates to Bills 108 and 109. While it is valuable that the acts recognize a variety of personal relationships, the codifying of such introduces limitations. For example, subsection 1(2) of Bills 108 and 109 state that partner relationships must be recognized by others. Many same sex and opposite sex relationships are covert owing to societal restrictions. While opposite sex relationships do not require the recognition of others, same sex relationships do.

In present practice, all significant people in a person's life can be included in a collaborative effort with the health care team to determine the values, beliefs and wishes of a person should he or she be unable to speak for himself or herself. The acts simplify the process for the health care practitioner but may not provide fully for the rights and care of the persons.

**Dr Webster:** My name is George Webster, and since 1982 I have worked as a clinical ethicist at St Michael's Hospital, St Joseph's Health Centre and Providence Centre in Toronto. I completed my doctoral work at Regis College in the Toronto School of Theology, University of Toronto, and I have an adjunct faculty position in the theology department of TST, as well as an appointment in the faculty of medicine with the rank of assistant professor in the departments of anaesthesia, obstetrics and gynaecology and medicine.

I wish to comment briefly on two points in the proposed legislation: first, the ethical principles underlying the substitute decision-making legislation and, second, the duties of guardians of the person and attorneys for personal care.

First, what are the ethical principles and values underlying the proposed substitute decision-making legislation? Should these be articulated in a more explicit fashion? What assumptions are made about the present health care system and what assumptions are made about the care giver/patient-resident relationship?

Many care givers view their professional relationship with patients and residents as a fiduciary relationship, one of trust. Care givers have expressed concern that the proposed legislation, especially Bills 74 and 108, as drafted, is based on the premise that the care giver/patient-resident relationship is an adversarial relationship. Further, the proposed legislation does not appear to recognize the legitimate advocacy role of health professionals in their relationships with patients and residents.

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Second, concerning the duties of guardians of the person and attorneys for personal care, specifically Bill 108, clauses 63(3)1 and 63(3)2, which read as follows:

"63(3) The guardian shall make decisions on the person's behalf in accordance with the following principles:

- "1. Any wishes the person expressed, orally or in writing, before becoming incapable shall be followed.

- "2. If the person has a power of attorney for personal care, any instructions contained in it shall be followed."

My concern is that guardians or attorneys for personal care are obliged to make decisions on the basis of any wishes, expressed orally or in writing, or any instructions contained in a power of attorney for personal care. I am assuming that we are considering patients or residents who are clearly non-competent, those lacking decision-making capacity.

Consider two case scenarios that are not uncommon that have posed very difficult moral problems for care givers, families and hospitals:

**Case 1:** An individual has prepared an instructional directive and communicated her wishes to relevant third parties, in this case family, that if she is seriously ill she wants everything done to prolong her life. She suffers a massive CVA, which is a cardiovascular accident, and ends up intubated and ventilator-dependent in our intensive care unit. Her prognosis for recovery is poor. Must she be continued on mechanical ventilation until she dies?

**Case 2:** A man has a massive bleed in his brain. The aneurysm is clipped and care givers expect a good recovery. Nutrition is supplied by tube and the man does not recover from the original injury and in time is diagnosed as in a persistent vegetative state. He has left clear instructions that he "would not want to be kept alive with tubes." Should feeding in this man's case be discontinued?

Many people have written an instructional directive but it is not clear how these documents have actually shaped treatment decisions. So-called living wills are often difficult to interpret because of language, definition and interpretation of terms and a certain indeterminacy concerning future circumstances. The purpose of an advance directive is to communicate one's wishes, values and beliefs concerning future treatment should one lose decision-making capacity. A difficulty with both the instructional directive and power of attorney for personal care is that we are asked to clarify now what our wishes might be some time in the future concerning possible treatment options, disability or withdrawal of therapy. This is a difficult task. Can we anticipate future circumstances? How informed is our decision now about some future state of affairs? Our perception of disability or deterioration now may simply not reflect the lived experience of those actually affected by a particular disability or disease process.

An advance directive or power of attorney may outline instructions, but third parties will have to interpret same. Many will interpret these documents in different ways. What exactly did the patient mean? Did he or she intend this to apply in these circumstances? Maybe the patient or resident has changed his or her mind, and simply cannot communicate this. How can we be sure now? Care givers often ask these questions about non-competent patients in residence. Care givers do not want to ignore the previous wishes of patients; they want to ensure that the interests of non-competent, vulnerable persons are protected.

In our present situation of limited resources, care givers find themselves in a conflict of interest. Patients may request or demand treatment that is seen to be futile from the care giver's perspective. In these cases care givers are often concerned that other patients are being denied beneficial treatment. Will guardians or those charged with the responsibility

of interpreting a patient's wishes or interests via instructional directive or power of attorney be free of this conflict?

In the first case, would guardians or attorneys for personal care be obliged to instruct care givers to continue treatment even if there was no hope for recovery? Would they be expected to follow any wishes or any instructions?

In the second case, would feeding be discontinued? Many people do not view the provision of nutrition, even by artificial means, as a medical treatment. It has been suggested by some writing on this question that not feeding another who is vulnerable and dependent "offends common human decency"—the notion that no one should die for want of food. Others are also concerned about homicide provisions in the Criminal Code, specifically, failure to provide the necessities of life.

How should care givers or guardians or attorneys for personal care respond? Must any wish or instruction be followed? Will this protect the interests of another who is truly vulnerable and dependent? Would this promote their wellbeing?

If care givers, guardians or those appointed as attorney for personal care must follow any wish or any instruction, a literal interpretation or uncritical acceptance of same may actually work against the interests and wellbeing of patients and residents.

**Dr Wong:** My name is Gerald Wong. I am a medical doctor who graduated from the University of Toronto in 1962 and became a fellow of the Royal College of Physicians and Surgeons of Canada in 1967. I hold the rank of assistant professor in the department of medicine at the University of Toronto.

Since 1971 I have been on the active medical staff at St Michael's Hospital, where I am a practising endocrinologist and director of diabetes services. I have been a member of the ethics committee at St Michael's Hospital for the past five years and have chaired the committee for the past three years.

This presentation will be about Bills 108 and 109 and reflect concerns about the possible impact of these bills on the practice of medicine at St Michael's Hospital.

St Michael's Hospital is a general hospital situated in the heart of the city of Toronto. Because of its location it receives, through its emergency department, referred by the police and ambulance services, many patients who are single, transient, estranged from their families and society and who may be incompetent to deal with decisions about their health care. St Michael's Hospital provides a full spectrum of medical, surgical and psychiatric inpatient and outpatient services to the community.

We are in general agreement with the spirit or philosophy of the proposed legislation, which encodes the rights of the patient or a recognized proxy to decide the nature of the health care to be provided by the medical community on his behalf. We have, however, several concerns about the procedural aspects of the bills and have fundamental difficulties with the understanding or interpretation of the legislation.

The definition of "treatment" in Bill 109 is open to broad understanding and may lead to serious disagreement in clinical decision-making. The scope or limits of the definition

are not clearly defined. A patient might demand treatment which is considered inappropriate by the health care team.

No distinction in the definition of treatment is made between different levels of care provided by the health care team. The degree to which consultation with the patient or proxy must be made before providing the different levels of care is unclear and may lead to a delay or paralysis of decision-making.

A common problem in both the emergency department and hospital population is the patient who is temporarily incompetent because of alcohol or drug intoxication. The appropriate procedural steps to make decisions and provide proper medical care for these patients in a temporary state of incompetence is not made explicit by the proposed legislation. The role of the advocate in this situation is uncertain.

The degree to which the requirements of the legislation must be carried out, especially when family members are clearly identified, is in question. Whether the legislation allows for latitudes of interpretation or flexibility in deciding the degree to which procedures outlined in the legislation must be implemented may be unclear in individual cases.

**Recommendations:** We recommend that the definition of "treatment" be clarified to establish the limits of care understood in the legislation. We recommend that some recognition of the various levels or degrees of treatment be included. We recommend that the common clinical situation of temporary incompetence from drug or alcohol intoxication be specifically addressed. Thank you.

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**Mrs Sullivan:** I am very interested in this presentation, because from the standpoint of one hospital, you have looked at these bills from an ethical point of view, and at all of the bills as they work in concert. I notice the queries you raise in relation to the ethical dilemmas in substitute decision-making and the adversarial nature of relationships which could result from the advocate versus the care giver or patient, and I notice that Dr Wong's presentation uses words such as "unclear," "uncertain," and "may lead to delay," questions relating to the ethical requirements of professional standards versus the patients' rights argument for information and consent.

It has been suggested by an ad hoc committee that includes the OMA, the hospital association, Ontario Friends of Schizophrenics and other groups that the series of bills be withdrawn and redrafted before any further procedure is done, or that the bills would have to be substantially amended before any continuation of their consideration. Would you concur with that point of view?

**Dr Wong:** Are you addressing anyone specifically?

**Mrs Sullivan:** Why do we not start with you, Dr Wong, because you are chairman of the ethics committee.

**Dr Wong:** I think the first thing to reiterate is that although we are not totally certain of what the philosophical and ethical bases of this legislation are, we support very much the idea of respect for the autonomy of the patient and assisting in making decisions about the kind

of health care he or she wants delivered on his or her behalf.

I emphasized in my report, and one of the readings is, that we are not lawyers. So when we went to look at the legislation to try to interpret this in the light of the kinds of problems we see in our emergency department or by the bedside or in our offices, we had a great deal of difficulty understanding what it was we were required to do and how compelled we were to do things.

So whether the legislation should be withdrawn and completely rewritten—I think the important point I am making is that it is very difficult for us who are not familiar with reading legislation to know how to take the requirements into our clinical practices, and we are having to deal with this kind of issue on a frequent basis in our emergency department or on a floor.

**Mrs Sullivan:** Certainly one of the very serious issues is that the complexity of the overlap in the legislation, given an area which is a matter of ethical concern anyhow, means that if the care giver does not understand the legislation, if the families and patients themselves do not understand what the requirements of the legislation are, how will we ever be guaranteed that any legislation put forward as a protective device either for the professional or for the patient will indeed be carried out? I think that is part of the basis for the concern about the drafting of the overlapping bills and why the suggestion is that this period should be used as a consultative period where people like yourselves come forward and identify the problems, and that the redraft would be appropriate at that point.

My understanding on the health bills, for example, is that there has not been consultation with those affected, particularly relating to consent legislation, since the time a paper regarding the principles of consent was issued by the previous government. My party is very concerned about not only the short-term impact of these three pieces of legislation on patient and care giver, but the ultimate cost for perhaps unnecessary purposes.

**Dr Wong:** Thank you very much for your comments. It was for this reason that I appended to my report a letter from the director of the emergency department at St Michael's Hospital to me and I thought it would outline very well the kind of dilemmas he is trying to face when he looks at the legislation, and then has a patient come into the emergency department.

**Mr Sterling:** I would like to thank you for your presentation and particularly your concern over Bill 74, which I think many groups have skipped over and perhaps should be paying more attention to. With regard to St Michael's Hospital, it having evolved from a religious background, what part, if any, does the church now play with regard to the moral and ethical standards of your institution at this time?

**Dr Webster:** The hospital still seems to be a Catholic hospital. It is owned by the Sisters of St Joseph of Toronto. I believe that in our deliberations around policy matters pertaining, as you know, to questions around termination of pregnancy etc, I understand that we would probably take around questions such as euthanasia—not withdrawal

of treatment, euthanasia—I think the teachings of our community would probably play a significant role in that.

**Mr Sterling:** Okay. So there is no formal structure as such, that the church intervenes in the ethical, but it is a historical thing.

**Dr Webster:** I think that is accurate, yes.

**Mr Sterling:** Okay. In your arguments, Dr Webster, with regard to advance directives, are you making the argument that you are better without an advance directive than you are with one, or is it that an advance directive should have no enforceability on the health care provider? Your argument seems to be here that these are bad, these are bad, these are bad. I guess I come to the inescapable conclusion, therefore, that you are better off without one than with one.

**Dr Webster:** In principle, there are major philosophical problems conceptually with the notion of instructional directives, and I touch on that. Around questions such as my trying to anticipate now what it will be like to live when I am a demented person in the special care unit of Providence Centre, or if I have a massive CVA and require feeding by nasogastric feed tube whether I would want that, I think it is philosophically impossible to know the kind of person we will be when we are no longer the person we are now. This is the point I am trying to make.

From my own perspective and in terms of the comments I made in my presentation, I feel that on your question about whether we are better without these, I think we are better with what we would call a power of attorney for personal care. I think we are probably in a better position to interpret the interests and wishes of another in situations that are actually present in the clinical context rather than trying to decipher and interpret what one means by something written six months ago.

Those questions I put in there are ones that care givers have asked me over and over again: "How do we know the people haven't changed their minds? How do we know they meant this about that? How are we to interpret this? Is that what they really meant? Did they say no tubes? Did they mean a ventilator or did they mean they didn't want to eat?" This raises, I think, vexing questions for care givers at the bedside. So in answer to the question, are we better without, I think no. I think we are better with some instruction about what I might want; about the kind of person I am; about what I value; about what is important to me, but I would want in terms of these proposals to tailor it, I think, as the legislation has, to a power of attorney for personal care model where someone can actually speak for you in the circumstances at hand. I think that may more accurately reflect their knowledge.

**Mr Malkowski:** Thank you very much for your presentation. It was very impressive. I would like to ask you a question: In any situation you have in hospitals where a person may come in intoxicated, under the influence of drugs or alcohol, what is your standard procedure now of dealing with those people? What do you do now?

**Dr Wong:** The procedure that is done at the present time—we are seeing this quite frequently—is that patients

are admitted to the emergency department of the hospital, their mental status is assessed and their medical status is assessed. If it is felt that they require some form of emergency treatment, then we try to persuade them that it is in their best interests to accept that treatment.

Of course the difficulty arises when the patient is belligerent, as he occasionally is. That makes it very difficult to know exactly what to do. In fact, if it is possible to persuade patients to receive therapy, if it is something like a laceration, for instance, then we try to persuade them. But I know there are patients, depending on one's assessment of the degree of incompetency and of the kind of medical disorder they have, who will actually be discharged without receiving any treatment at all.

**Mr Malkowski:** We have heard from different individuals and some from the Ontario Psychiatric Survivors' Alliance, who shared their experience with us at this committee. They told us that when they go to a hospital they are sometimes mislabelled and misdiagnosed—some schizophrenics, for example. Sometimes families and physicians work in concert and then they find out later that this person has been mislabelled. Whom would you follow in that situation, the wishes of the patient or those of the family? Do you not think it is important for an advocate who can perhaps express the needs of that individual with respect to respecting his autonomy?

**Dr Wong:** The procedures through which you go in a situation in which the medical problem is psychological or psychiatric is a history taken with the patient and/or with the people who can give information about the illness, a physical examination that will include a mental status examination of the patient and an attempt to determine whether that patient is competent to make a decision about the kind of health care the physician and the medical staff feel is appropriate for the kind of medical problem that patient has.

If a decision is made that the patient receive some form of treatment but the patient is not able to agree with that, once again you are into a great difficulty about how to determine the degree to which the care that is felt appropriate, on the basis of the history and physical examination, should be offered to that patient. Frequently, what will happen is that a third party is brought into this, and it is frequently a psychiatrist, who attempts to help make the decision about whether or not that patient is competent. If the patient is deemed by a third party not to be competent, then we may proceed with treating the patient. If it is deemed by the third person that the patient is competent, then we have to allow the patient to make the decision about his or her health care at that time.

**Dr Webster:** Could I respond briefly to Mr Malkowski's question? Some time ago I was consulted by our emergency department about a young fellow who was in the end stage of his disease. He was suffering from HIV and AIDS. He had taken an overdose of barbiturates in a downtown hotel and he woke up the next morning and called emergency. The ambulance brought him into emergency and he needed some treatment and refused it. In this situation the question from the care giver's perspective

was, "Is the person capable?" By "capable," I mean, does that person have decision-making capacity, given what he had earlier evidenced from his actions to third parties. "Is this person's refusal now an informed one?" To me, the critical issue here is how we go about assessing decision-making capacity, and it is a very difficult question.

**The Chair:** Ms Prentice, Dr Wong, Dr Webster and Ms Walkerley, on behalf of this committee I would like to thank you for taking the time out of your busy schedules and giving us your presentation this morning. This committee stands recessed until 1:30 this afternoon.

The committee recessed at 1235.

## AFTERNOON SITTING

The committee resumed at 1345.

**The Chair:** I call this committee back to order.

LORNE MARTIN

**The Chair:** Dr Martin, good afternoon. As you know, you will be given a half-hour for your presentation. The committee would appreciate if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucus members. As soon as you are comfortable could you please identify yourself for the record and then proceed.

**Dr Martin:** My name is Dr Lorne Martin and I am from Oakville. I appreciate the opportunity to appear before the committee. Approximately nine years ago I was a resident in psychiatry at the University of Toronto working at the Clarke Institute of Psychiatry. I want to relate a short story to you.

I remember one of my patients being wheeled on a stretcher down the hall into the elevator. She was a 24-year-old schizophrenic patient. She was being taken for electroconvulsive shock therapy and she was being taken against her will. She did not consent to the treatment; that consent was provided under the act by a member of her family. As she was going down the hall screaming, "You have no right to do this to me"—it had been done to her before—the psychiatrist, realizing that I was a little sensitive about issues of consent and in fact thought it a very odd thing that psychiatric patients should have the right to refuse treatment, explained to me in a rather clever fashion that she really was consenting to treatment. The reason was that the healthy part of her ego would clearly agree to something that was good for her and that what we were listening to were symptoms of her disease that therefore could be disregarded.

As you might have already guessed, I quit my residency in psychiatry and eventually ended up in family practice. I now work as a family physician in Oakville and also as an emergency physician. I also hold the chair of the department at my hospital and I am the chairperson of the bioethics committee at my hospital. I would like to suggest, perhaps differently from other presenters you have had at this committee, that there is a group of people in our society whose rights are routinely trampled on: the psychiatric patients, specifically in psychiatric institutions. Nearly every hospital in this province has a locked psychiatric ward and all you need to get in there is a physician's signature. I myself find this alarming. I have always found it alarming.

Initially when I heard about bills 108, 109 and 110, I was very excited in thinking that perhaps some of these wrongs would be redressed. In reading through the bills, I am not sure if that is the case. I would like to tell you a few other stories. I think they get the point across more pointedly.

I had another patient who was 45 years old and who had spent the better part of 20 years in various psychiatric facilities: the Queen Street Mental Health Centre and then

more recently the Clarke Institute of Psychiatry. This was ostensibly for his own wellbeing. His stays were three to four months at a time, and he would always be out in the time between his admissions. Every time he was an inpatient he was there against his will. He had to be locked into the hospital ward. He would try to escape. He was there because he was a danger to himself and to others, the traditional Mental Health Act justification. The only infraction he had ever committed was that at age 17—he was now 45—he had once driven his car through a parking barrier and had a high-speed chase up the Don Valley Parkway. There were no injuries. This justification emerged at every admission. For that he spent the better part of 20 years in a psychiatric facility.

I had another patient who was a schizophrenic—at least that is what he was called by the psychiatrist—who had been in the hospital continuously for 18 months. What crime did he commit? He threatened his room-mate with a knife—a very serious infraction, I suppose. There was no judicial hearing. He had no way of protecting his own rights. Every single day that he was in the hospital he demanded to know from the psychiatrist by what authority he was incarcerated. You will be glad to know these were the psychotic meanderings of a schizophrenic patient and could be ignored, as all communications from schizophrenic patients can be.

1350

The problem with schizophrenia is that it is often a dispute between the patient and the family or the patient and society. The patient is always disruptive and alarming and concerning and almost always bizarre, and it is often the consequence of psychiatric admission and treatment that the dispute is resolved. It is resolved in favour of the more powerful party, and that is not the patient. When a patient and a family member are in the assessment unit or in the emergency department, it is the family member who is listened to, because the patient is mentally ill. All his or her communications are discounted on this basis.

I said that when I first saw these bills, I thought they might resolve some of this difficulty and return to the psychiatric patients some rights they deserve and very badly need. But in reading through the bills—please correct me if I am wrong—I feel that the power of attorney, which I think many psychiatric patients would be capable of exercising, is subordinate to the power of the guardian.

It seems to me there are a number of ways the power of attorney may be got around. The way I look at things, I am trying to understand how the psychiatric profession and its responsibilities to society may try to get around a power of attorney. I can certainly imagine some of my patients writing these things up, and I see that when a person is thought to be in a state of emergency, this authorizes psychiatric admission and treatment and gives broad powers to a psychiatrist. Do not get me wrong; I am sure they are all well-meaning and I am sure they believe what they are doing is good, but I do not and many of their patients do not either.

Psychiatrists cannot predict the future behaviour of people. That has been shown in study after study. They cannot predict the dangerousness of a person, nor can they predict when a person is going to kill himself. Naturally they deal with a segment of society in which suicide and aggressive behaviour are more common, but that is about as specific as you can get, and with the individual they have no powers whatsoever. Yet the Mental Health Act requires me, in my capacity as an emergency physician or a family physician and a psychiatrist to admit someone to hospital when he or she is at risk. You can only guess how this is acted upon out there in the streets. The risk is to the psychiatrists if they do not admit a patient and he does something. The Mental Health Act gives them that responsibility now. That forces them, or at least puts a heavy weight on them, to be conservative in admitting the patient if there is any question. I do not think these bills are going to change that.

The explanatory section of Bill 108 says: "The fundamental principle of the act is that the wishes capable persons express must be respected even if they later become incapable." I could not agree more wholeheartedly.

I would like to suggest some specific changes to the acts that I think may help the psychiatric patient in making this a reality.

I believe guardians should be bound in law to validate instructions of the power of attorney, and as I read the act they are not. I also suggest that the process of validation of the power of attorney should be made automatic upon admission to the psychiatric facility, and that the process of establishing a power of attorney be automatically facilitated through the advocate on admission to a psychiatric facility. That could be done whenever the patient is found to be capable, or presumably at discharge.

I suggest that the power of attorney be effective in refusing psychiatric admission and treatment. You might wonder what then happens to the so-called dangerous patient and what authority the psychiatrist would have if my recommendations were to be accepted. My point is only that if we are going to incarcerate somebody, there should be a formal judicial process and a person's rights should be respected. They should have their opportunity and their day in court.

That really is the substance of my presentation. I wanted to speak directly to the members of the NDP in the committee. The NDP was instrumental in some recent changes to the Mental Health Act that did enlarge the rights of mental patients, of the so-called mentally ill. These were important but they are completely ignored in our hospitals today. I think there is much that could be gained by these bills. I will not speak about all the other excellent aspects of the bills, including the ability to create something like a living will, which I see very much as an advantage. Thank you.

**The Chair:** Questions and comments. Mrs Carter.

**Ms Carter:** I think in a sense you have broken the mould. We are seeing a pattern emerging of one type of group. We actually had a coalition this morning, which included the Ontario Friends of Schizophrenics, the Ontario Hospital Association, the Ontario Nurses' Association, and

the association for community living. They have reservations about the bill, but we also have quite a long list of groups who are supportive—I am talking about Bill 74 here. They seem to be the more down-to-earth consumer level. We have psychiatric survivors, People First, who believe in the humanity of severely disabled people and so on.

I just wonder from what you said, do you really have any problem with Bill 74? It is consumer-oriented. That is the whole point of it: to empower the vulnerable person himself or herself. It is to say, "Well, whatever somebody else says is good for you, you have the right to make your own decision, even if all the professionals and so on say you are wrong."

**Dr Martin:** This is the Advocacy Act you are speaking about.

**Ms Carter:** Yes.

**Dr Martin:** I do have some reservations, and it is only because the motivation of the psychiatrists and of psychiatric treatment is always the best interests of the patient. It is my own opinion that the only way to really protect those interests are to let the person himself or herself say what those interests are, and the rest of us can all be damned. I really believe that, and I am not sure that that bill has that intent. Really I focused my comments on the power of attorney because I feel that they do, and I feel that it is the most powerful aspect of the bill in protecting people's rights.

**Ms Carter:** But leaving the other bills out, if I can, and focusing on Bill 74, I do feel that as far as that goes, it is definitely what the consumer thinks that has to be taken into account and passed on by the advocate.

**Mr Fletcher:** Just a couple of quick things. We have had a lot of presenters coming forth. Some of them have been schizophrenics, some of them have been parents of, and some of the schizophrenics themselves are saying, "I'd like to sign a form that says that when I'm in a delusional state I can have a person designated to make sure I get treatment." That goes along with your thinking?

**Dr Martin:** I have no trouble with that whatsoever. That extends the rights of that person when he is capable to the time when he is incapable. A small percentage of psychiatric patients will choose psychiatric treatment.

**Mr Fletcher:** As I say, we have had presenters come in who are parents, and some of the stories I have been hearing about the schizophrenics' state—wandering the streets, no shoes in a cold winter, just right out of it. Now you are saying that this person could say, "No, I don't want treatment," and that is okay?

**Dr Martin:** I am absolutely saying exactly that. I would like to respond by saying that there was a time in the 19th century when a man could commit his wife to a psychiatric hospital without even a physician's order, and it would be just that type of circumstance. Sometimes the only way a person has to rebel against the situation he is in is to become disordered and disorderly. I think this was the case at a time when women had no rights; this was one of the only options left to them.

I am not trying to downplay. It is a terrible problem, having a person like this in your family, and it is not going to be necessarily the fault of anybody. It can be a terrible problem. I am only saying that the resolution of the dispute must respect the rights of all parties. That means that if we are talking about incarceration and if we are talking about treatment, the person has to have a judicial process to defend those rights.

**Mr Fletcher:** I was thinking of the parents or friend or relative—my heart goes out to them—who watch the person go into this state. They have lived with the person for so long, yet they do not have the respect for his decisions either. Do you find more families are disruptive when it comes to treatment or are they sincerely trying to help but maybe going the wrong way? I do not know. I am trying to understand it myself.

1400

**Dr Martin:** They are in a very difficult plight. We do not have a lot of time, but I guess I would like to say a word about treatment. The treatment we give for schizophrenic patients is major tranquillization. It basically takes the lifeblood out of you: It eliminates your sexual drive; it eliminates all aggressive drive; it makes your problems very small because you do not care; you become apathetic. That is what the treatment is, and if the problem is a person who is really disrupting the family because of his behaviour, it works in the sense that it solves that problem, and obviously hospital admission solves that problem as well.

I am only once again saying the rights of the patients are being trampled, and the treatment itself is extremely damaging. Long-term treatment with the anti-psychotic medication causes damage to the functioning brain—permanent damage. I have patients, a number of them in senior citizens' homes now, and I cannot take them off the medication because they have permanent brain damage and taking them off the medication brings the symptoms out. So the treatment is in my opinion a bad thing. I believe the incarceration is bad, I believe the drugs are bad for the patient, and a lot of those patients believe so too.

**Mr Winninger:** I appreciated your submission and I just wanted to explore with you a couple of your recommendations because I am not quite clear in my own mind on them. First of all, you said that you do not believe the guardian is bound in law to follow the wishes of the vulnerable person. I would just say that we do have section 63 included in Bill 108 to address that very concern, that the guardian or attorney for personal care carry out the wishes and instructions of the person.

**Dr Martin:** That is right, but I think if it is seriously meant that the attorney could not be gone over by the guardian, then you would not have the inclusion that the attorney is suspended when the guardian is appointed. And also it says there—and I am taking a lot from the language—that the guardian is bound in principle. In other words, if the guardian does not want to respect the wishes of the attorney, he or she does not have to go to the courts. It is just a guideline there for the guardian, so I feel it is not strong enough.

**Mr Winninger:** Okay. To take your second point about the guardian overriding the attorney, just to make sure we are both clear on this, it is my understanding that an attorney would have to be terminated before a guardian would be appointed, that there would be no compelling reason to overturn an executed power of attorney for personal care.

**Dr Martin:** If I am a schizophrenic patient and I appoint someone to be my power of attorney and then I am behaving in such a fashion that everyone believes I need to have hospital admission, someone applies to the courts for the appointment of a guardian and that is the end of my power of attorney. That is how I see it.

**Mr Winninger:** Right, but at that point the power of attorney is terminated. Is that something you find desirable or not?

**Dr Martin:** No. I think the power of attorney should remain in effect. I feel that if the guardian wished to go against the power of attorney, that should require a judicial process.

**Mr Winninger:** If the attorney who was appointed in all confidence by the donor of the power of attorney turns out to be a bad choice and makes all kinds of unwise decisions, should there not be any constraints on the way that power is carried out?

**Dr Martin:** That is right. I guess there is a balance of risk there, but it is my own opinion that is much less of a concern than the power that is already there and that I feel will remain despite these bills.

**Mr Winninger:** Okay. The last point was your recommendation that there be a power of attorney to refuse psychiatric treatment. Was that a more specific kind of power you were suggesting in your third recommendation?

**Dr Martin:** That is right, that the power of attorney include the power to refuse psychiatric admission and treatment. In other words, I am suggesting the unsuggestible, that this act supersede the Mental Health Act, which I realize is probably completely unfeasible, but this is the problem.

**Mr Winninger:** So you acknowledge that it is problematic?

**Dr Martin:** I am sorry, politically?

**Mr Winninger:** To override the Mental Health Act, because some people have come and presented a case that there should not be civil commitment at all.

**Dr Martin:** I agree with that.

**Mr Malkowski:** Your presentation this afternoon was fascinating. Sometimes there is perhaps a patient who has been misdiagnosed as schizophrenic, or another issue we talked about is treatment and how the treatment can have worse side-effects, or long-term side-effects, on the patient. Do you have any studies or research on how common that is, how often it happens in terms of misdiagnosis or the ill effects of the treatment on a patient?

**Dr Martin:** It is a very interesting question that you ask and a difficult one to answer. There are no objective criteria—and my psychiatric colleagues, if there are any around, will be bristling—for the diagnosis of schizophrenia.

It is not like the diagnosis of a myocardial infarction where there are objective criteria; we are dealing with an organic process that can be defined. Schizophrenia, in the tradition of psychiatry, is what psychiatry calls schizophrenia and it is a very nebulous thing and very difficult to define. It is impossible to present a study saying how often it is misdiagnosed because I do not believe there is a clear diagnostic criterion.

As far as the harmfulness of the treatment, it is estimated that 30% of patients who have long-term anti-psychotic use end up with permanent brain damage, and that does not comment on the fact that people currently taking anti-psychotic drugs are having their brain function interfered with, because these are major tranquilizers.

**Mr Sterling:** I find your presentation interesting. One thing I think is of interest is that if you were to terminate a power of attorney through getting guardianship, that automatically points to a court process, and I do not understand your concern about that particular part. In other words, if I went for the guardianship of a person I deem mentally incompetent who had a power of attorney, then I would have to go through a court process to terminate that. I was watching Mr Winninger ask you questions and watching counsel behind him, and I think that is what he was thinking.

What happens when people who care about their son, daughter, brother or whatever know that something is dramatically wrong, they determine that their son or daughter is suffering from schizophrenia, or the symptoms appear to be that way—how do they remedy the situation in your scenario? If this person is suffering from this dementia and part of the dementia is to reject treatment because of paranoia, how do you deal with that person in society?

**Dr Martin:** It is part of what I would call a psychiatric myth that psychiatric patients reject treatment because they are paranoid or because they are demented. I believe they reject it because it makes them feel terrible. I guess my own suggestion is that if we are going to provide asylum or aid to this type of person, we are going to have to find a way to do it that is acceptable to them.

**Mr Sterling:** Given that the present medical technology is that you have to use drugs of some sort to deal with it, then you are suggesting there is no acceptable treatment at this time.

**Dr Martin:** I am suggesting that you do not have to use drugs. I am suggesting that this is really not a medical act when we use psychiatric drugs. This is a social and political act and I think it has to be understood as substantially different. It is not like a heart attack where I use a clot lyser to open that vessel back up; that is medically indicated treatment. We are using these drugs to quiet these people down because their noise is extremely disruptive to their family or society. They are standing on the curbside screaming in a bizarre fashion. We are using the drugs to shut them up. In my opinion, it cannot be defined as medically indicated treatment.

1410

**Mr Sterling:** I have been somewhat involved with attempting to have a medical drug approved in the province of Ontario: clozapine. People who have had the opportu-

nity of using that and Dr Barry Jones from the University of Ottawa and the Royal Ottawa Hospital say that schizophrenic patients who are treated with this become more productive. They are able to return to school; they are able to become contributing members of society. And yet you would say clozapine is no good.

**Dr Martin:** Have you had here any groups of psychiatric patients treated with this drug telling you how wonderful it is?

**Mr Sterling:** Yes, there have been.

**Dr Martin:** There have been?

**Mr Sterling:** Yes. Not in this committee, but I have read the testimonials of these people.

**Dr Martin:** You see, one has to be careful. A lot of the excitement about new treatment comes from the profession, and we have to be, right off the top, very sceptical. One has to be sceptical with all the new drugs that come on the market. Often a new drug comes on the market greatly heralded and ends up with its reputation sullied for one reason or another.

Yes, this is the latest fashion, but in the last 20 years there have been a number of drugs come that have been the "breakthrough" in schizophrenia, and I have seen them come and go. That particular drug has a one in 100 incidence of aplastic anaemia, which is potentially fatal.

**Mr Sterling:** Yes. That is why they test every week for it.

**The Chair:** Thank you, Mr Sterling. Dr Martin, on behalf of this committee I would like to thank you for taking the time out this afternoon and coming and giving us your presentation.

**Dr Martin:** Thank you very much.

#### SCHEDULING OF PRESENTERS

**The Chair:** Our next presenter is not here. This is the second time he has been scheduled, so I think it is important that the committee have a brief discussion on the facts surrounding this and see how we can make it possible for him to attend. He is being held on a Lieutenant Governor's warrant and is having difficulty in getting released to come and give his presentation.

We have discussed with him about a teleconferencing session, and he is not really agreeable to that. He would like to come in person. Being that this is a person who has not been represented in this committee by anybody, we feel it is important that he does attend. Maybe Lisa could fill in some of the details.

**Clerk of the Committee:** Essentially, this person has been scheduled twice and would like to appear before the committee. In consultation with the Chair and the Vice-Chair, because one of the issues was financing to bring him down, an offer has been made not only to pay his costs of coming down, but also to pay the costs of the two people who would have to accompany him. The hospital still said no after that was offered to him, and the hospital is suggesting that he be teleconferenced. As the Chair just said, he is rejecting that as an option.

That leaves us with a couple of options in terms of this committee. One is to again offer him the teleconferencing—I guess to issue a stronger invitation. He has asked me to bring before this committee the option of the committee issuing a Speaker's warrant that the hospital would then have to comply with to allow him to come down.

**The Chair:** Personally, from the Chair's perspective, I would recommend against the Speaker's warrant, because basically what we have done has been to have an open invitation for people to come and give presentations; we have not subpoenaed anybody. So I am not really looking at that as a viable option, but I am in the hands of the committee.

**Mr Winninger:** I think we should reiterate our strong desire that he be allowed to attend here but without issuing the Speaker's warrant, and indicate perhaps that in our view his public right to attend and make a submission is being effectively denied. These days, when our federal electoral reform committee is looking at expanding the rights of prisoners and also people on Lieutenant Governor's warrants, I think we have to be mindful that we may be denying him his civil rights if we do not issue a strong, perhaps imperative, invitation to have him attend with his security guards present.

**Mr J. Wilson:** Why is he on a Lieutenant Governor's warrant?

**Clerk of the Committee:** I have not asked.

**Mr J. Wilson:** I do not think you can brush aside, just because he is on a Lieutenant Governor's warrant. There may be good reasons why the hospital has denied the request.

**Mr Mancini:** Yes, those were the questions that were going through my mind also. Let's find out what the details of this warrant are. If we cannot talk about it in open committee, we can talk about it in camera, or the subcommittee can deal with it. But for us to speculate about something we do not know anything about is difficult, and we will take it from there. It is hard to make a decision without all the facts.

**Mr Fletcher:** I can understand the concerns of the members, but I think what David said about a strong invitation would be a sensible way to go. Whether the person is on there for whatever reason should still not be a deterrent to the person being able to testify before this committee. I do not know why the hospital is deciding whether or not he should testify, and I think that in itself is an infringement on a person's civil rights. I really do not want to get into the legal aspects of a warrant or a subpoena or anything. I think what Mr Winninger was saying was just to issue a strong invitation. If that fails, then we have done our best.

**Mr Mancini:** I think we are playing games. If my friends across the floor feel that strongly about it, we have the right to ask for a Speaker's warrant, which has been done in the past, has been implemented in the past. So let's not say that we want the gentleman here and we are going to send a strong opinion to whomever and we are going to protect this gentleman's rights by doing that. He should be able to come. If the gentleman cannot come, well then, that

is the end of it. If you really want the person here, you issue a motion, you ask for a Speaker's warrant. If the Speaker agrees, it is signed and the person appears. But before we go to those drastic steps, let's find out what the nature of the Lieutenant Governor's warrant is all about. Who knows, maybe we might join with you in a Speaker's warrant once we have all the information. But do not tell us you want the guy here but then you do not want to issue a Speaker's warrant.

**Mr Sterling:** A warrant like this is usually against a person who is dangerous to other people in society. I do not understand the great concern about this individual when we turn off hundreds of other individuals who come from faraway places from appearing in front of committees, which would cost the committee, unless they have some special knowledge with regard to the bills and there is some feeling by members of the committee that those people's ways should be paid to come in front of a committee to express their opinion about whatever. I suggest we ask this individual to write a brief, and then if the members of the subcommittee feel that he has some special knowledge which we should have in front of this committee, then we deal with that at a later time.

**The Chair:** The Chair would entertain any motion as to the direction the Chair should take.

**Mr Sterling:** I suggest we ask him—if a he; I was not certain—to make a written brief. If the subcommittee feels there is some special contribution this individual can make to this committee, then we look at it further at that time.

**The Chair:** That is in the form of a motion?

**Mr Sterling:** Sure.

**The Chair:** Discussion?

**Mr Malkowski:** I am not sure it is fair for us to question this person's right to—he obviously wants to come to the committee, but we are requesting he write a brief. I think we may not have enough information whether they can do that. They may not have the resources available to get the help they may need in writing such a brief. I think we need to keep that in mind as well.

**The Chair:** Further discussion?

**Mr Mancini:** I think Mr Malkowski is correct. We are asking this gentleman to write a brief, and we do not know, given the circumstances, if the person will have the proper assistance, or in fact would be able to do what we are asking him to do. We changed the subject entirely. A few minutes ago the subject was how we were going to get this person before the committee and what steps we were going to take to get this person before the committee. We seem to have abandoned that for the idea of having this person write us a brief. I think we are dealing with two separate matters, and I have not heard a conclusion on the first one yet.

**The Chair:** Just as background, the presenter has refused to submit a brief.

1420

**Mr Sterling:** I think he has been offered a television hookup where he can talk. He does not have to present a brief, then; he can give a tape or whatever. There is some

concern that our committees not expend public dollars to excess in a recession. I think it is important that we hear as many stories as we can, but we also have to be cognizant that every time we write a cheque it means that our deficit for this province becomes greater etc. I do not understand this discussion when many committees turn down hundreds of individuals who want to come and make a public appearance in front of committees.

If I have no idea, and this individual refuses to tell us what his problem is about in some form and we have offered him some alternatives, then that is too bad.

**Mr Fletcher:** I agree with what Mr Sterling is saying, that if we have offered for a brief and that is not good enough, then fine; so be it. Why do we not just take this one to the subcommittee and let it deal with it at another level? You do not have your motion. I will make a motion to that if we need it.

**Mr Sterling:** I do not think we need another motion.

**The Chair:** We have a motion on the floor already.

**Mr Fletcher:** Yes, I know there is.

**Mr Sterling:** I will withdraw that motion. Can we refer this to the subcommittee?

**Mr Fletcher:** That is a good motion. Thank you.

**The Chair:** Any discussion on the motion to refer it to the subcommittee? Seeing no discussion, all those in favour? Opposed? Carried. If possible, could we have a five-minute meeting of the subcommittee right after adjournment today? Thank you.

#### DYING WITH DIGNITY

**The Chair:** I call forward our next presenter, from the Dying with Dignity group. Good afternoon. I remind you that you will be given a half-hour for your presentation. The committee would appreciate if you would keep your remarks to about 15 minutes and allow time for questions and comments from each of the caucuses. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Mr Elliott:** Thank you, Mr Chairman. My name is Donald Elliott. I am a retired lawyer and I am the president of Dying with Dignity. With me is Marilynne Seguin, who is a registered nurse and who for the last seven years has been the executive director of Dying with Dignity. On behalf of our membership I would like to say to this committee and to the government that we want to express our support for this legislation, in particular for those parts of Bills 108 and 109 that will give legal authority to living wills and powers of attorney for personal care.

At the present time, with very few exceptions, every adult in Ontario who is mentally and physically competent has the common-law right to make his own decisions about his medical treatment. The problem is that there is no way that an adult in Ontario can make decisions about his future treatment and have it authorized, and at the same time there is no way that an adult in Ontario can appoint an attorney to act for him when he or she is unable to make those decisions. This legislation corrects that problem.

As I said, Marilynne Seguin has been involved with Dying with Dignity for more than seven years. She is a

great lady and she has counselled many families and their loved ones when they have had problems at the end of their lives. I would like to call on Marilynne to give some instances from her experience as to how this legislation can help those situations.

**Ms Seguin:** I welcome the opportunity speak to this committee this afternoon. As you will see on page 1 of our presentation, Dying with Dignity speaks for 6,500 Canadians, approximately half of whom live in Ontario. In 1991 we received requests for assistance at the rate of 1,000 calls a month. We have no idea of what the statistics will be in 1992, except that they are considerably higher than this rate.

Mr Elliott is much more qualified and will address the legal concerns we have with this legislation. I believe my own unique experience with the dying and their families allows me to address some of the very urgent human concerns these bills could remedy.

As a registered nurse and the executive director of Dying with Dignity, I am often called upon to counsel those persons who are nearing the end of their life. In the last few years we have started keeping a few records on this, and I have been at the bedside of over 300 people at the moment of their death.

To demonstrate the problems which so desperately need your support through this legislation, I would talk to you about four people—friends, clients, whatever we want to call them—who died fairly recently. Of course their names have been changed to protect their privacy.

On page 2 you will see the stories of Eva and Harry. Eva was an elderly lady who had suffered a great deal in her life. Six years ago she had suffered a stroke of major proportions. Her son had removed her from her home and admitted her to a nursing home. Since that time he had more or less decided that his mother no longer existed and had chosen not to be involved with her. The one complication was that he held a power of attorney for her property. There was some confusion at the nursing home where she resided that this also gave him the right to make some decisions about her health care.

Eva had decided about two years ago that she wanted to be responsible for herself and to be taken seriously about this. She had signed a living will in which she decided what care she would choose to have for the rest of her life and those treatments she would refuse should certain circumstances evolve.

A couple of weeks before the end of her life, she developed pneumonia, and the fears she had in place became a reality. She decided she would not choose to be resuscitated should she have cardiac arrest. She did not wish to be treated with antibiotics, which had given her terrible reactions and so on before. She made a number of choices. However, the physician in charge of Eva's care phoned the son and said, "What would you like me to do?"

The son indicated he wanted everything possible done to keep his mother alive but, to quote, "Just don't bother me about it." The physician was in error in that he believed the power of attorney gave him the power to ignore Eva's wishes. This legislation could change that confusion.

1430

Harry is quite a different situation. He is 55 years old. He was a virile, vibrant man, a mover and shaker sort of person in the manufacturing business, and he was as dexterous with his hands as he was agile with his mind. He had always controlled everything around him and felt a great need to have that power. For four years now he has been suffering from Lou Gehrig's disease, which steals away all the muscular-neural ability. He could no longer walk, turn, go to the bathroom, blow his nose, dry his tears or any of the other physical functions that many of us take as an ordinary part of our everyday life.

Harry had decided, knowing the course of Lou Gehrig's disease, that there were certain decisions he wished to make. If his respiration failed, he did not want to go on a ventilator. If his throat filled up with fluids, he did not wish to have a tube put down to withdraw all those fluids. He felt this would be undignified and not in keeping with his own sense of integrity.

In order to facilitate this, he asked Debra, his wife, to assume power of attorney for health care. She was quite willing and able to do so. The physician said he would recognize this. However, such permission does not exist under the present law and it would need to be enacted under the legislation you are discussing today.

Sadie is on page 3 of your material. Sadie was a grand old lady, centre of a large, noisy family, and she was being very well cared for in a large Metropolitan Toronto hospital. But suddenly, at 6:30 on Friday night, Sadie had a premonition, if you will, a feeling, a very strong feeling that comes to a great many people who are close to death that she would die soon, and she wanted this to be at home with her family, with her husband, Jake, and her noisy grandkids. The physician, who took very good care of her, was away for the weekend. A new physician was put in charge of her case and said: "Absolutely not. I will not discharge her home. Who is going to be responsible for her?" Without a power of attorney, he felt he could not honour her wishes and she was not allowed to go home. I think this legislation could remedy this serious problem.

Joseph was a slightly different story in that it was a physician who contacted me to ask for help to take care of Joseph's problem. Joseph had come to Dying with Dignity about a year ago and told me he had terminal cancer. He seemed very well in control of the situation. He wanted to sign a living will, which he did. He personalized it with the care he would like to receive and what he would not accept. What we could not foresee was that at the ninth hour, literally, the night he was expected to die, his elder brother arrived on the scene and threatened the physician, saying: "If you allow Joseph to die, there'll be big trouble. I haven't finished my business with him and I will not permit you to allow him to die." Joseph too, as well as his physician, needed the new power this legislation could give him.

Eva, Harry, Sadie and Joseph illustrate only the tip of a very vast conundrum faced by thousands of patients, their families and their health care workers every day that passes without clear, precise guidelines in these agonizing medical and legal and social issues. The dilemma addressed

by these bills must be resolved and it must be now. Mr Elliott will proceed with our legal concerns on these matters.

**Mr Elliott:** Thank you, Marilynne. As I said in my opening, as a society, Dying with Dignity supports this legislation, but perhaps because I am a lawyer and because during my professional life I was in the medical-legal field, I feel, and the committee that looked after this with our group felt, that there were some changes that should be made to this legislation to make it more people-friendly.

Our first problem has been with validation, and if you will return to page 4 of our submission you will see what I am referring to. Bill 108, subsection 47(9) provides that, "The power of attorney is not effective until it is validated in accordance with section 49."

I have given my wife power of attorney, and if she was required to use that power of attorney because I could not make medical decisions for myself, this is what she would have to do: She would have to make an application to the public trustee and guardian. She would have to supply him with copies of the power of attorney and statements of two assessors, probably a psychologist and a psychiatrist who would have examined me as to my capacity to make medical decisions for myself, then she would require a guardianship plan. If at that time the public guardian and trustee desired, he could appoint an advocate who would come and speak to me about this situation, report back to the public trustee and guardian and then, if the public guardian or trustee decided he would not validate this power of attorney, it could go to the courts. If in the long run my wife was successful in getting this power, then as of December 31 in each year she has to make a report to the public guardian and trustee as to all the decisions she has taken under the powers that have been given to her.

We say that this is far too complex, that a solution could be found which would be much more appropriate. The Law Reform Commission of Alberta has been considering legislation to this effect and has this document. We have made copies available to you. They have considered that problem, and have in my opinion a much more appropriate and succinct way of dealing with it.

Another problem we have is with the execution of these documents, particularly the power of attorney. We feel it could be made much more simple. As you may know, the courts in Ontario have held that for a Jehovah's Witness a simple printed statement that has been signed by the person is a direction to any doctor who sees it, and that even though the patient is unconscious he no longer has the right to give a blood transfusion to that person. The courts have accepted a simple execution of a document like that and we feel it would be sufficient, simpler and much easier to handle if that was all that was required of these documents—that is, the power of attorney.

Something we would like to see added to the legislation is that the power of attorney, whoever that person is, should be required to accept the responsibilities under that power of attorney by saying he does so and by executing the document. I do not want to be surprised some time to be called by the hospital saying that one of my friends has appointed me as his power of attorney and now they need a decision from me as to his treatment. I need to have

discussed the matter with that person. I need to know what his or her values are and what they would wish in these particular circumstances. We feel it is particularly important that the person who is willing to be the attorney for the grantor should be required to execute that document.

1440

On page 5 we talk about a couple of matters, revocation of directives and divorce, and we give suggestions on how those two headings could be made much simpler.

We also want to talk about another addition to the legislation, which is the effect of existing documents. This is the so-called grandfather clause. We suggest a clause we would like to see added to section 23 which would make all documents—living wills and powers of attorney that have already been executed in this province or elsewhere when they come to this province—legally authoritative as well.

One further addition we would like made is that there should be an onus on medical practitioners to inquire as to whether there is a living will or a power of attorney for personal care. In the legislation it is provided that the doctors must inquire if there is a near relative who can assist with these decisions. We suggest that they should also be required to inquire as to whether either or both of these documents are available in order to assist to make those decisions which are necessary.

One further matter we would like to suggest to the government is that, if and when this legislation is passed, there be given a great deal of publicity to it through the media. We find that there are many, many people in this province who have never heard of living wills, never heard of what we call durable powers of attorney and are unaware about their rights to make their own decisions if they are *compos mentis*, so we would suggest that the government make a large effort to see that these matters are publicized.

There is one last request we would like to make, and that is that if there are any changes to the legislation which are going to be suggested by this committee to the Legislature and if they affect the interests of the Dying with Dignity society, we would appreciate it very much if we could see what those amendments are and have an input about them.

We are very grateful to Norm Sterling, who really started this, to Ian Scott and to the members of the NDP—Frances Lankin, Howard Hampton and Elaine Ziemba—for bringing this legislation forward. It has given a great deal of hope to a large number of people here in Ontario and we would like to commend those people for their help.

There is just one other matter I would like to put forth for your consideration, and that is that if these four bills are going to take a lot of time in your consideration or it is going to be very contentious or take a lot of amendment, to consider whether it is possible to excise those parts which affect living wills and durable powers of attorney, or if there might be some possible way of reinstating and considering Mr Sterling's Bills 7 and 8 so those matters can be considered, as I say, expeditiously. Thank you, and we are of course prepared to answer any questions.

**The Chair:** Thank you. Each caucus has about three minutes for questions and comments.

**Mrs Sullivan:** I have been very interested in the work you have done in the past and the efforts Mr Sterling has made in presenting Bills 7 and 8. I did not sit on the committees when those bills were considered, but we are confident that most of what he has put forward has been incorporated into these acts.

I have been interested, though, in some of the limitations or ethical questions that arise as a result of advance directives or living wills, and I would like to put some of these to you. I know there is not much time to respond; forgive me, Mr Chairman. One of them relates to directions that are ambiguous or that may relate to an illness or disease or occurrence that is foreseen today, when indeed the medical or ethical question that comes to the fore relates to a very different factual and medical situation: whether one illness was contemplated or whether there has also been a change in the status and practice of medicine over that period of time. That is one area.

Another thing has been put to me quite forcefully by many health care providers. I have been concerned about parts of the legislation that eliminate or virtually eliminate tissue donations, for example. One of the things I am told by providers in the field now is that even with a licence, which appears to be a useful and simple documentation of an advance wish, if a patient comes in, particularly in a traumatic situation, whether it is a car accident or a workplace injury, nine times out of 10 that documentation is not found. Either the police have it or it has not been located.

You talked about the difficulties of execution and the difficulties of the health care professionals delivering the service being very clear. How do you see those things being brought together in terms of a completely redrafted, we hope, legislation that will be workable?

**Mr Elliott:** Maybe I can answer. First there is, and always has been, the problem with living wills that they may be vague or unclear and difficult to make out in accordance with the particular situation that has arisen. It is almost impossible to think of all the varieties of things that could happen to us and make the proper requirements for those happenings. That is why the power of attorney for personal care is so important, because that individual then stands in the place of the patient and the doctors then can speak to that person. They can tell him or her what the diagnosis is, what they are considering doing and what the prognosis is. Then, on the basis of the values known by the attorney of that particular person, he or she can make a decision as to whether he will accept or will not accept that particular treatment.

You are right; in many instances the living wills can be vague. The power of attorney overcomes that and the living will in effect acts as a kind of philosophy of the person even though it does not exactly fit the situation that may happen. It will give everyone—families, powers of attorney, the proxy—it will give them the feeling and the values of that person and they will be better able to carry out what that person would have decided if he had been *compos mentis* at the moment.

**Mr Sterling:** I would like to thank my two friends who are in front of this committee this afternoon. I have had numerous contacts with them over the last two years, since I started sort of the legislative thrust for this.

Mr Winninger mistakenly portrayed my legislation as being dead. It is as alive as Bills 108 and 109 are in a formal sense at this present time. I have voluntarily stood back, because I thought there were some advantages in the government legislation over mine and have made that clear in writing to other members of the committee. I have only suggested that we keep it there in case something happens to Bills 108 and 109.

1450

Dying with Dignity brings forward several areas of concern over the formality of drawing advance directives. In light of all those suggestions I would like to ask Mr Winninger why such a formal requirement, as set out in your legislation, is needed.

I think what Mr Elliott has said in response to Mrs Sullivan's question is that the advance directives, other than the power of attorney, particularly the living will, cannot be perfect regardless. I do not think anybody can draw one which will cover every base or whatever it is, but there is going to have to be some interpretation to it, dealing with powers of attorney, dealing with property at this present time. We entrust the validity of that instrument to the person who is trying to exercise the power. Why are we requiring such a mesh of regulation and formality to these documents?

**Mr Winninger:** I may give a very general answer and then I may ask Mr Fram if he has any additional comments to make.

First of all, we are reposing some very extensive powers in the attorney for personal care here, very extensive powers to consent to treatment or not, to make a number of important decisions that affect the welfare of the vulnerable individual. I think it is important that the formalities be safeguarded to a considerable extent. We all know of cases of abuse in the past, even with powers of attorney for property, where people have been coerced into granting powers of attorney and then the attorney does what he or she wishes with the property. In this case, by having those formalities in place, just as we do with the will, requiring a couple of signatures, people who are not related to the donor of the power of attorney, we have some assurance that this power of attorney reflects the wishes and instructions of the donor.

I am sure Mr Fram can elaborate on this.

**Mr Fram:** I agree with Mr Winninger's comment. The other thing is that the past history of execution of powers of attorney for property was such that these safeguards were directed at trying to improve that we do not get incapable people appointed powers of attorney for property.

Then we came to the next decision, which is, should we have two different sets of witnessing requirements? The answer was no because quite often people will go in and do both at the same time. That would be needlessly confusing, so we kept the same set of witnessing require-

ments for the power of attorney for property as well as the power of attorney for personal care.

The other thing of course is that this goes beyond just medical decision-making. It goes into ongoing guardianship type of situations, of ongoing powers, unlike just a medical proxy. We felt that since these powers may be ongoing over a long time those provisions would be helpful.

**Mr Fletcher:** Just a couple of things, one right off the bat: We have been waiting a long time for this legislation to come through and I have already commended Mr Sterling for his foresight in getting this off the ground. In fact, I commend the Conservative caucus for trying to make amendments that will make these bills a lot better. I think that is one good way of looking at it. As I say, you have waited a long time, and we heard a group this morning and we heard the Liberal caucus say, "Scrap everything." Can you wait? Can you scrap it and wait another two or three years, as far as your people are concerned?

**Mr Elliott:** We would be very unhappy if that happened.

**Mr Fletcher:** I thought so. That is why when I looked at the press release from the Liberal caucus about scrapping everything, I thought: "No, no. People have waited too long. We have been in the trenches too long." As I said, Mr Sterling has fought long enough to try to get this through. Just from my own personal experiences, I agree; it has been too long.

**The Chair:** Thank you, Mr Fletcher. Very briefly, Mr Wessinger.

**Mr Wessinger:** Just a quick question with respect to your comments concerning validation. I assume you are aware that under section 16 of the Consent to Treatment Act, "The incapable person's attorney for personal care under a power of attorney that confers authority to consent to the treatment but has not been validated under the Substitute Decisions Act" can give a consent. I assume you are aware of that.

**Mr Elliott:** Yes, I am. But I am also aware that in Bill 108, under 5, explanatory notes: "A person may give a power of attorney for personal care. The power of attorney comes into operation only when it is validated by the public guardian and trustee on the basis of evidence that the person is incapable." In looking at this, Alberta has suggested that their reading of it is that it must be validated. I keep thinking to myself, suppose my wife wants to validate it on the Friday afternoon before Labour Day. We live up on a farm north of Brampton. Where is she going to go and how is it ever going to be validated?

**Mr Wessinger:** Then what you would really like is some clarification in the Substitute Decisions Act, because it is clear under the Consent to Treatment Act that they can give the consent. You are concerned that there be some clarity made.

**Mr Elliott:** Or that somebody would require validation, and what would you do then? You say: "Well, look at what the act says about it. It does require validation." I think it needs clarification and I think that in Alberta they have the right idea. If my doctor says he thinks I am incapable of

making these decisions and he is going to call on my wife, and I say, "No, I can make those decisions," then he is empowered to call in another doctor. If that other doctor agrees with him, that is all that is necessary. Then my wife has the power to make the decisions for me. That is in effect what this legislation is saying, because it requires two assessors to make decisions about me, and those two assessors are very likely to be doctors. It seems to me that it is much simpler, much more uncomplicated, and it answers all of the problems there might be.

**Mr Wessinger:** I would just like to indicate that it is certainly the intention of the Consent to Treatment Act, and it is clearly in that act, that with an unvalidated power of attorney, the person who has the power of attorney can give that consent to treatment. But as you say, maybe there may be some need to clarify that.

**The Chair:** Mr Elliott and Ms Seguin, on behalf of this committee I would like to thank you for taking the time out this afternoon to come and give us your presentation.

**Ms Seguin:** In case people in the room might not have seen what a new, good living will looks like, I have brought some copies with me. If anyone would like to have them, they are welcome to them.

**The Chair:** If you would give them to the clerk, I am sure she would distribute them to any committee members who would like them. Thank you very much.

#### ALLIANCE FOR LIFE (ONTARIO) INC

**The Chair:** I would like to call forward our next presenters, from the Alliance for Life, provincial and national. Good afternoon. As you know, you will be given a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, please identify yourself for the record and then proceed.

**Mrs Weidinger:** I am Regina Weidinger. I am on the national board of the Alliance for Life, and a board member for Ontario. I am from Cambridge.

**Mrs Jeffs:** My name is Jakki Jeffs. I am the executive director of the Alliance for Life Ontario. I hope you have my oral presentation before you. On behalf of the Alliance for Life Ontario, I thank the committee for its work over the last few months on the proposed legislation. I have with me today a member of our national board, Mrs Regina Weidinger, who is present on behalf of our national association.

Alliance for Life Ontario represents 80 educational pro-life groups that work under an educational mandate to promote respect and protection for all human life from conception to natural death. We number approximately 50,000 members in Ontario and have a national membership of close to 200,000.

We have many concerns with the direction of both the Ontario government's proposed legislation and the two private member's bills.

1500

Our Ontario office first became aware of the government principles from a Dying with Dignity newsletter dated January 9, 1991. Marilynne Seguin, the executive

director of Dying with Dignity, stated in reference to the legislation, "It is an important piece of work...and might eliminate the need for further legislative initiative in Ontario by Dying with Dignity."

You might better understand our concern with Ms Seguin's support of this proposed legislation when you hear two other comments made by her. In 1987 she was quoted in the *Globe and Mail* as saying: "The bottom line is economic. We can no longer afford to keep thousands of people alive as human vegetables and the AIDS question will bring this into strong focus." In 1988 she stated in the *Ottawa Citizen*, "It is unnecessary to legalize the living will in Canada, since all individuals in this country already possess the right to refuse medical treatment."

The organization Dying with Dignity distributes its own version of a living will and also a euthanasia declaration document. With Ms Seguin's focus on economy and her callous reference to terminally ill persons as "human vegetables," her support of the government bills is considerably distressing to our association.

Alliance for Life Ontario has been studying government Bills 74, 108, 109 and 110 and we applaud the initiative to ensure that incompetent Canadian citizens are protected and their rights ensured. However, we believe there is much confusion caused by the legislation and wish to confirm the following concerns.

Bill 74 and the definition of "vulnerable": "In this act, 'vulnerable person' means a person who, because of a mental or physical disability, illness or infirmity, whether temporary or permanent, has difficulty in expressing or acting on his or her wishes or in ascertaining his or her rights."

It was our initial understanding that this legislation was directed to those who are permanently incompetent. With this definition of "vulnerable," each of us, having lost competence temporarily for whatever reason, could be assigned an advocate under this legislation. Consequently, it is feasible to say that a person could be assigned an advocate with power to make decisions concerning health who would then override the vulnerable person's spouse or family.

Bill 109, An Act respecting Consent to Treatment, subsections 7(1) and (2): We are extremely concerned and confused by this section. Are we to understand that if a person becomes incapable even temporarily within the meaning of the act, the person holding the power of attorney for health care becomes the decision-maker? This situation cannot be overridden by the incapable person, even if he or she becomes capable again. According to our understanding of Bill 109, subsection 7(2), that person will be unable to regain power to make his or her own health care decisions.

In many sections of Bills 74, 108 and 109, mention is made of an advocate explaining the rights of a vulnerable person to the vulnerable person. How does an advocate do this if the person is mentally incompetent to make decisions or understand the consequences of those decisions? Surely these persons will be unable to understand what rights are, let alone their implications or application. In theory this sounds extremely democratic, but it does not seem to be a workable option given that the persons being

addressed are considered vulnerable or incapable within the terms of this legislation.

Subsection 10(1) of Bill 109, An Act respecting Consent to Treatment, reads, "When a health practitioner finds that a person who is 16 years of age or more is incapable with respect to a treatment, the health practitioner shall," and the following subsections elaborate on the procedure with respect to advising the person of the findings, meeting with the advocate, and exception, assistance and treatment delay.

Subsection (7) states, "This section also applies if the person is less than 16 years of age and has demonstrated a wish to give or refuse...on his or her own behalf."

We are most concerned at the apparent absolute neglect of the parental rights and the rights of the family of the incapable person mentioned in this section. Are we to believe that if a child of eight informed a health practitioner that he did not want to undergo treatment to which his parents had agreed, then an advocate would be informed and assigned to the child? What about the parental rights in this case or the rights of the families who have loved and cared for these individuals? Do we really believe that a state-appointed advocate knows more about what is best for the child than the parents who have loved, reared and cared for that child?

We have found this proposed legislation extremely complicated and confusing and we fear that, rather than helping vulnerable persons, the system that these bills collectively initiate appears to be fraught with ambiguity.

We are dismayed to see that the government is proposing to set up a structure which seems to give the power of health care to a bureaucracy and take it away from individuals, parents and families. I would like to illustrate that with one case that happened in the United States, and which I believe could happen here under this system should this legislation be passed. Mary Hier was 92 years old and had lived in hospitals for more than half her life. She thought she was the Queen of England. She was not terminally ill, but because of a non-malignant defect she had received food by means of a gastrostomy tube for over 10 years. In an unexplained incident, that tube became dislodged. The care facility sought to replace the tube, but her court-appointed guardian refused permission. The court, agreeing with the denial of permission, stated that implanting the tube was highly intrusive and a highly risky procedure.

Just as Mary Hier's case was being reported in a Boston newspaper, another story appeared in the same paper. It concerned a 94-year-old woman who was doing well following minor surgery to correct a nutritional problem. The surgery was performed on an outpatient basis under local anaesthesia. The woman's name: Rose Kennedy. The minor surgery: insertion of a gastrostomy tube. For Mary Hier, elderly, demented and without family, it was described as highly invasive and highly risky. For Rose Kennedy, matriarch of a rich and powerful family, it was minor medical procedure.

Only last-minute intervention by a Massachusetts physician, Joseph Stanton, and attorney Harry Ledoux, resulted in Mary Hier's tube being reinserted. At last report, Mary Hier continues to live comfortably and happily, still signing her name "Mary Hier, Queen of England."

Will vulnerable people like Mary Hier fall prey to the same kind of discrimination under the advocacy system? Will an advocate's decision on treatment override the patient, spouse and family, and rule all-powerful in a case like Mary Hier's?

We believe these bills should not be passed because they appear to set up an almost overwhelmingly complicated system whereby the state is gradually taking over the individual's decision-making power in the area of health care.

Concerning the private member's Bills 7 and 8, it is our understanding that currently a spouse or family member already has the right to make decisions on behalf of a spouse or family member. We can see no reason for this legislation, which appears to confer by law what is an inherent and practised right already.

Bill 8: We are totally opposed to this bill and request that it be defeated. It contains wording that can be so broadly interpreted or, indeed, has been so inadequately defined that it is dangerous. Our questions are: What does "life-sustaining procedure" mean? Are nutrition and hydration included in this definition? What is the definition of "medical procedure" or "treatment"? Many patients are on strict diets ordered by their doctors. Would this be included under treatment? There is no distinction made between ordinary or normal care and extraordinary care. Would this legislation mean that comfort care such as cleansing and toilet would be denied to a person? The definition of "terminal" is infinite. Taken in its broadest sense, we are all terminal from the day we are born.

There is at present an initiative in the United States by the Hemlock Society to include those in coma or persistent vegetative state within the definition of "terminal." Is that the understanding in Canada? These people, for the most part, are not terminally ill, although there is not much hope for an improvement in their situation.

#### 1510

Bill 8 talks about "incurable, irreversible conditions." How are these terms defined? Will they include diabetes, asthma, arthritis? What is the definition of "imminent"? Two days, two weeks, six months, a year? There is no age limit given for the witnesses. Are we to understand that a person of any age qualifies for this position, even if he or she is incapable of understanding what he is witnessing?

In section 3 we read that a living will of a person is not valid if the person is pregnant. While we find nothing else to applaud in this legislation, we are pleased to note that the life of a pre-born child is protected in this proposal.

Under liability, section 6, it says that a person is not liable for damages to a person under the living will. The withholding or withdrawal of a life-sustaining procedure, which under this legislation could be as simple as food and water, results in the starvation and dehydration to death of a person. Is this not homicide? We question whether this legislation has the power or authority to redefine homicide. What is even more shocking to us is that a person only has to say that he believed the living will was valid and the previous section would protect him from punishment.

There is no definition of "health care provider" for the purposes of this legislation and therefore this opens the

door to even wider abuse. This legislation also apparently totally disregards the conscience rights of health care personnel. What would happen if a health care provider could not in good conscience, either for personal, ethical, moral or religious grounds, take part in an act of omission under this legislation which would hasten or cause the person's death? This bill stipulates that a conviction of a health care provider under this legislation would be no more than \$1,000 and imprisonment for not more than a year. We find it hard to understand how a piece of legislation that can be so broadly interpreted is so narrow in its concern for those who are unable to comply with its direction. It would appear that if you are willing to cause or hasten someone's death by withdrawing or withholding treatment, you will be protected under this legislation. However, should you be unable to participate because of personal, ethical, moral or for religious reasons, then unless you move "promptly," which once again is not defined, you could find yourself facing a huge fine and a year in prison.

In section 7, for the purposes of life insurance, it would appear that there is an attempt once again to redefine homicide. In section 9, while the bill states, "This act does not create a presumption as to the intention or wishes of a person who has revoked or has not executed a living will," we believe the presumption will be made that those persons without living wills will require everything to be done.

In conclusion, we remain in total opposition to both the proposed Ontario government legislation and the private member's bills. The fact that the Dying with Dignity group supports these legislative initiatives and the history of similar legislation in the United States confirms our position.

The living will, given force of law, is neither a benefit nor protection for people. Health care providers will be placed in unthinkable positions, and society is being duped into believing that living wills are necessary to protect doctors from patients and vice versa. The structure to protect health care providers who will assist, cause, or hasten someone's death by withholding or withdrawing life-sustaining procedures is being established. It will not be long before the lethal injection is seen to be a much more compassionate means of death than allowing persons to starve and dehydrate to death. The pro-euthanasiasts have called the living-will legislation the crack in the ice to begin the process of decriminalization and acceptance of active euthanasia and assisted suicide. We strongly recommend that this committee does not take into consideration the economic advantages of the living will, which by stripping people of their right to good medical care has the financial benefit of saving thousands of tax dollars. As a society, we believe it is our duty to care for all innocent human beings and to never sanction or indeed take part in their deaths, especially under the insidious guise of living-will legislation, which purports to empower people but in fact leaves them totally vulnerable.

We respectfully submit our submission to you.

**The Chair:** Thank you. Each caucus will be given about five minutes for questions and comments.

**Mrs Sullivan:** Once again we appreciate you coming before the committee with your views. I notice on page 3

you talk about the legislation being complicated and confusing and you fear that "rather than help vulnerable persons the system which these bills collectively initiate appears to be fraught with ambiguity." That is a matter of great concern to us in the examination of the bills. Along with many health care providers and agencies, we have called on the government to use these particular bills simply as consultative documents and put them forward in a redrafted form.

We certainly concur with the view that a codification of consent is appropriate, that a codification of substitute decision-making is appropriate and that advocacy for people who are vulnerable is appropriate, but these particular bills are so badly drafted and so confusing that neither the health professional nor the patient nor the substitute decision-maker, were that the case, would benefit from this particular package of legislation. I wonder, given your views about the ambiguity, the confusion and the collectivity of the bills, if you would concur with that position and make that kind of recommendation.

**Mrs Jeffs:** I am not sure if I could. Certainly I would be happy to take that back to our association and discuss it. I come to this without a legal or medical mind. My position as executive director lays this job squarely on my desk. I have looked at it very simply as a Canadian citizen and mother and part of a family with children. Maybe that is where part of the confusion, for me at least, would come. I am really pleased to find you have had the same problems but at a different level.

**Mrs Sullivan:** Is that not an important aspect of this, that these bills have to be understood not only by the health practitioner and by the lawyers but by the people who are going to put them into effect?

**Mrs Jeffs:** I totally agree with you.

**Mrs Sullivan:** You have talked about the confusion and you have talked about the ambiguity and the lack of clarity and understanding. That is certainly a matter of grave concern to us. We would appreciate it if you did go back to your board with that suggestion and ask it if it could respond to the committee perhaps even before our hearings are over.

**Mrs Jeffs:** I will certainly do that.

**Mr J. Wilson:** Thank you very much for your very interesting presentation. I cannot believe my colleague Mr Sterling could write such terrible legislation. It is as bad as the government's legislation.

**Mrs Weidinger:** Maybe he should have asked us for input before he wrote it.

**Mr J. Wilson:** He did of course cancel the debate in the House on his legislation when the government brought forward these bills. We are learning a lot during this process.

When it comes to care in the hospital or in a health care setting, when is enough enough? It is a common question I am sure you get asked. We already heard the Minister of Health and the deputy minister talk about rationing health care after age 70. They have already been quoted in the Globe and Mail as saying that so far it does not seem economically feasible to be giving people replacement

lung operations after age 70; the economics of it are not justifiable in a health care system that is starving for cash. You can see there is a trend developing that your group is well aware of and fighting. I think the question in layman's terms is, when is enough enough?

**Mrs Jeffs:** I do not think anybody would disagree that there is a time when further surgical treatment or medical treatment can be finished. Up till now one assumes all the patients, doctors, health care providers and families have been able to make that decision. What I do not understand is why all of a sudden we feel that is not being done or that there is confusion and we wonder if every patient who has been in hospital up until now has been overtreated. The living will part of this private member's bill does not necessarily address that.

**Mr J. Wilson:** To answer your question, we are living in an increasingly legalistic society and the world is becoming so. Who makes the decision? You say leave it up to the health care practitioner, who says his current practice—but many of them want increased protection, I guess, under the law if they are to make those decisions. Maybe that is the route we should have been taking.

1520

**Mrs Jeffs:** Actually, I would really like to see—I presented on Bill 203 at the federal level, too, and the same comment was made there that many of the doctors want protection. But a doctor has not been taken to court in Canada, right?

**Mr J. Wilson:** Not in Canada.

**Mrs Jeffs:** Where are the doctors? Let's have some type of factual statistic that says most of the doctors are worried to death that what they do or do not do is going to get them in a court case.

**Mr J. Wilson:** As Health critic, I have had doctors in my office tell me that. In fact, many of the things they are doing now, taking extra tests and extra precautions, are for the very fact that they are worried someone would take them to court for not doing everything reasonably possible within their means right now to preserve life. When a socialist government is leading a discussion on rationing health care, then I tell the citizens of Ontario they had better be worried and you had better address these issues.

**Mrs Jeffs:** I totally agree with you, and I think most of our—or at least my own concerns really come from the United States since 1977, when they went through this same type of debate, this argument for living-will legislation because doctors should be protected and patients have to be protected. When everything finally came down and the dust settled they realized that the way they were working before was quite okay.

But now all of a sudden we have living-will legislation which does not benefit patients. It actually means they give up their health care, which does save tax dollars. The latest initiative 119 in Washington state came from the Senate finance committee and, yes, that does scare me, that we have now a price on life, a price on health. To start seeing that it is now age-discrimination-based really does worry me.

I think the whole system needs looking at, not just the elderly, the disabled or the terminally ill—the people who are already in the hands of the health care providers. They are the vulnerable people, not competent people, but those vulnerable people.

**Mr Sterling:** Given that a living will is a legal document in Ontario and Canada at this time, does it not make more sense to you to try to formalize the document to some degree to ensure that it has been properly witnessed and properly attested to when the person was competent to make that living will? Does it not make more sense to enshrine it in legislation than leave it as it is?

**Mrs Jeffs:** Does a living will actually have the force of law?

**Mr Sterling:** Yes.

**Mrs Jeffs:** I was not aware that it had, to be honest. I think the living-will legislation you propose, which I had assumed gave force of law to advance directives—

**Mr Sterling:** No, it formalizes it.

**Mrs Jeffs:** It formalizes it. Okay. What I do not understand about it is that the living wills have to be so broad. You are asking somebody when they are competent, fine, to make medical decisions based on a time, however many years ahead, and situations they cannot foresee. You might be in a car accident. You might have had a stroke. How do you make those so specific in order to protect that person, because the scenarios are trillions, are they not? How does that legislation do that?

**Mr Sterling:** There is no legislation now, but it—

**Mrs Jeffs:** How would your legislation do that? How would your legislation protect people so when they put “withdrawal of treatment” it does not mean withdrawal of everything a year, two years before they die? If they have an incurable disease—which, by the way, diabetes is—how are they protected?

**Mr Sterling:** Basically you protect the person in society, I guess, in terms of any kind of written instruction he might have, to make certain that the person was competent when he said what he was saying and that people who witnessed the document were not benefiting from the fact that this person might die or whatever, in terms of the treatment.

I am just intrigued. If it is the law at the present time, which I believe it to be, that you can make a living will, by formalizing it you will have better living wills in the end, because they will be more specific, and you will not have people who may or may not have been competent making them. There will have to be determination by the witnesses that these people were competent.

**Ms Carter:** I understand your fears, but really, I feel there is no necessary connection between what we are proposing and unauthorized withholding of life support services or euthanasia for economic reasons. I do feel that you have slightly misunderstood Bill 74.

On page 2 you are saying a “‘vulnerable person’ means a person who, because of mental or physical disability” and so on, “has difficulty in expressing or acting on his or her wishes or in ascertaining his or her rights.”

You are assuming that this person is really unable to express those wishes, where I think it is clear that it is meant to apply to people who maybe have difficulty, but nevertheless do have wishes that if somebody takes the trouble to ascertain they can express. The advocates are not meant to be dealing with people beyond the point where they really can express any wishes.

Now, we have had this point argued to us, that if you pay close enough attention people can usually get messages through, but the intention is to ascertain the person's own wishes, so when you say an advocate's power to make decisions concerning health would then override the vulnerable person's spouse or family, I do not see that danger because, by definition, it is going to be the person's own wishes.

Having said that, I think what worries me and probably a lot of people is the cruelty of keeping people alive beyond a certain point, and of course modern technology has meant that people's suffering can be prolonged to a much greater degree than might have been possible when natural death would have overtaken them at an earlier point.

I thought I would ask you to comment on the Nancy B. case that we all know about, and which has just happened, which was a clear instance of somebody who decided that her own life was not worth living and those wishes were ultimately acted on.

**Mrs Jeffs:** I guess we disagree a little there. The Nancy B. case, in my understanding, was a right-to-refuse-treatment case, which she had every right to do. I believe she decided at that point that the respirator was too burdensome for her and had it switched off. I really was amazed to see it come to the courts at that point and I actually made the comment that it was being used by the euthanasia people to once again cloud the issue, because the issue is very clear around the Nancy B. case legally.

**Ms Carter:** So you would have no problem with that?

**Mrs Jeffs:** No, I do not have a problem legally, but I think in my heart, yes, I do. I wonder, why was she where she was? Was she offered all options? Was she depressed with that disability? There are so many questions that come to mind; but as a strictly legal case over right to refuse treatment, no, of course not. She had every right to do that.

**Ms Carter:** To me, ultimately that is what is important, that the person herself can make the decision, whether at the time or, if she wishes, previously. Thank you.

**The Chair:** Mrs Weidinger, Mrs Jeffs, on behalf of this committee, I would like to thank you for taking the time out of your busy schedule and coming and giving us your presentation this afternoon.

1530

#### ALZHEIMER ASSOCIATION OF ONTARIO

**The Chair:** I would like to call forward our next presenters from the Alzheimer Association of Ontario. As you are aware, you will be given a half-hour for your presentation. The committee would appreciate it if you would keep your comments to about 15 minutes to allow time for questions and comments from each of the caucuses. As

soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Mr Trueman:** My name is Peter Trueman. I am the spokesman for the Alzheimer Association of Ontario on this occasion. With me are John Ellis, the executive director of the Alzheimer Association of Ontario, and Wayne Gay, a lawyer on the association's board. I hope these two gentlemen will be able to answer any questions you may have that I cannot handle.

Let me say on behalf of the Alzheimer Association of Ontario how very pleased we are to be able to make this presentation before Bills 74, 108 and 109 proceed any further. The association, although in sympathy with the intent of the legislation, is afraid its application would needlessly complicate care giving and medical treatment for Alzheimer's patients by adding a complex and unnecessary layer of external decision-making.

In terms of Alzheimer's disease, the legislation has the effect of trying to fix something that is not broken. We feel that the three bills would create administrative backlogs and long delays in treatment, might put a damper on research, could result in higher costs for families and an even larger health services bill for Ontario taxpayers.

I must say that those of us who have had long experience with Alzheimer's and are aware of the sacrifice and dedication patients get from a vast majority of care givers resent the intrusive, somewhat paternalistic tone of the legislation, particularly as applied to members of Alzheimer's sufferers' families. Thus we believe that Bill 74 should be abandoned and the remaining legislation should be revised.

I would like to make it clear at the outset that I am no expert on Alzheimer's, senile dementia, or other forms of cognitive impairment, although I have had some firsthand experience with disabling illnesses in relatives and close friends.

This would mean nothing, however, if my wife and I had not also been the primary care givers for my late mother. She lived with us from 1984 until it became necessary to have her admitted to a chronic-care facility about a year ago. Since it was and continues to be up to me to make a living, it was my wife, of necessity, who was under the most strain. I will be for ever grateful to her.

In my estimation, only primary care givers and medical specialists can have any idea how debilitating the illness can be, not just for the patient but for those who choose to look after them. Mercifully, my mother died two months ago, within a decade after Alzheimer's disease was first suspected. She would have been 89 at the end of January.

Before I go on to a critique of the legislation, I would like to make some basic points about Alzheimer's and the nature of the illness. In this age of computers, it is easy to overlook the fact that the only memory bank which is indispensable for human existence is the mind. For the growing number of Canadian care givers who live with Alzheimer's victims, this is a simple truth that is underlined starkly and relentlessly every day.

The incidence of Alzheimer's is rising sharply, in part because diagnostic techniques have been improved, but mostly perhaps because people in general are living so much longer. The older one is, the greater the risk. Once a

Canadian reaches the age of 65, for example, the chances of contracting Alzheimer's are nearly one in 10.

In 1990, some 300,000 Canadians were believed to have Alzheimer's. There are 120,000 in this province alone and their numbers are expected to rise by about 50% over the next decade. When you compare such figures with those for other—some of them higher-profile—illnesses, you begin to realize that Alzheimer's has become one of the major afflictions of our time. In that same year, 1990, in Canada, there were some 200,000 known cases of ileitis and colitis, 60,000 cases of Parkinson's disease, 50,000 cases of multiple sclerosis, 20,000 cases of muscular dystrophy and 2,500 cases of cystic fibrosis.

Alzheimer's has become not simply a major medical problem numerically. It is a horrible illness, not just in what it does to the victims but in what it does to those around them. Little is known about what causes it and there is no known cure for it. The patient never improves, although there are frequently long periods in which little change is obvious.

Autopsies show that the nerve endings in the cortex of the brain degenerate and disrupt the passage of electrochemical signals between the cells. As the disease progresses, according to one of my layman's reference books: "The changes in the nerve cells produce simple forgetfulness and increasingly more noticeable memory loss. Changes in thought, language, personality and behaviour can eventually render the person incapable of taking care of himself or communicating his needs to others."

More than many other illnesses, Alzheimer's is a family disease. If a wife gets it, for example, it means that her husband must face not only the gradual loss of his life's partner but the gradual emergence of a new dependant. Before my father died in 1988, it was the loss of the woman he loved rather than the transformation from partner to dependant which tried him most deeply. I will never forget the agony in his voice when he told me how out of touch mother was becoming and how difficult he was finding it to keep his temper in the face of increasingly circular conversations.

I know what he went through, because when he died it was I who bore the brunt of these repetitive, open-ended dialogues, and I am no saint either. There were times, I know, when my impatience showed as I answered the same question a dozen times in the course of half an hour, times when my eyes must have glazed over after the fifth or even the 10th repetition of the same anecdote. The only point of interest after one has heard the same story that many times was the subtle ways it changed from repetition to repetition. Who said what and to whom could alter slightly. Even the punch-line could acquire a new emphasis. This was a painful process for someone who knew all the stories and who loved the storyteller. Our memories, after all, are what define us as people, and when we lose them we begin to lose our identities.

Although this is hard on loved ones, of course it is immeasurably worse for the victims themselves. Mercifully perhaps, they become increasingly confused and uncertain about what is happening. It is frequently obvious to care givers, however, that they realize something is terribly

wrong, even if they cannot put a name to it. The sufferers become frightened about their unavoidable voyages into the unknown.

Ultimately, the Alzheimer's victim loses not only the spouse, whom he or she no longer recognizes, but sons and daughters, grandchildren, great-grandchildren, relatives, friends and colleagues. In the advanced stages of the illness, those who have it live in a world of strangers.

At some point literacy vanishes. Victims find it increasingly difficult to write completed sentences because they cannot hold a train of thought. Mother would labour for half the afternoon to make an entry about the weather in a diary she had been keeping with ease for years. Those who escaped into books all their lives, like mother, find suddenly that they can read no longer because they forget what they have read on the previous page or even in the previous paragraph. Mother read and re-read the first page or two of the same detective story, a favourite Agatha Christie, almost daily during the last few months she spent with us. She could not get beyond the opening sentences.

With the memory loss, the patients lose all experience and can no longer look forward to life's small pleasures because they do not remember what they are, and so in the end they lose themselves. They may forget how to tie their own shoes and when to go to the bathroom. They forget ordinary household dangers—stairs, fire, electricity—and cannot be left on their own unless they are somehow immobilized.

Personalities can change. Men and women who never raised their voices to anyone can become caustic, argumentative and aggressive. Agreeable people can become negative about everything.

They can forget their own names and where they are. Sometimes they develop a distressing tendency to wander. Wandering may be caused by stress in a new situation or unhappiness in an old one. Patients may set out to revisit an old stamping-ground and forget the route or destination. They may lose sight of the person who is supposed to be looking after them in the middle of a busy supermarket or shopping centre and become disoriented.

Losing the memory does not simply end intellectual growth, it reverses the learning process. When memory fails us, we revert eventually to childhood and ultimately to infancy. This is no less wrenching for the care giver than it is for the victim.

The care givers, given all the pain, time and effort involved in looking after an Alzheimer's patient, ought to be treated like an endangered species. They deserve more, in our view, than this legislation.

There is, of course, community support for the person looking after a loved one with Alzheimer's. First and foremost, there is the Alzheimer organization itself and its many local chapters. There really is comfort in shared experience. In my own area in Kingston, the Victorian Order of Nurses operates an Alzheimer's home program in which VON nurses lend a weekly hand with bathing and hygiene. Local programs provide companions and homemakers two days a week. In Kingston, at least, St Mary's of the Lake Hospital, God bless it, takes in patients for a month at a

time to provide some much-needed respite periods for home care givers.

1540

But there comes a time, even with all this help, when keeping the patient at home is no longer possible. It may be a matter of the patient's safety, it may be a failure of the care giver's will and nerve, it may be simple exhaustion or it may be a marriage that is beginning to come apart under the strain. There may be unbearable financial pressures. Whatever the reason, sooner or later common sense dictates that the patient go to a long-term care facility, if one can be found with a vacancy. In my experience, when that happens, no matter how pressing the need for relief, care givers are frequently assailed by feelings of guilt. They feel they have not done enough, that perhaps they should have tried a little harder to bear the burden a little longer.

The care givers I know who are members of the Alzheimer association are wonderful people. They deserve to be supported not just by society around them but by their governments. We should all be doing everything we can to make their tasks easier, not more difficult. And more difficult, in my view and in the view of the Alzheimer Association of Ontario, is precisely what this legislation is likely to make it.

The Advocacy Act, Bill 74, is particularly inappropriate for Alzheimer's sufferers. The act seeks to empower the disabled who have difficulty in expressing or acting on their wishes or in ascertaining or exercising their rights. To ensure that the Advocacy Commission deals with them fairly, the act stipulates in section 6 and others that "A majority of the members of the commission shall be persons who have or have had a mental or physical disability, illness or infirmity." Let me assure you that with Alzheimer's there is no one who fits the "have had" category. It is a progressive illness and it is inexorable. Its victims do not recover and return to productive lives. I would like to know if the members of this committee really believe that someone suffering from the illness I have spent the last few minutes describing could add anything to the deliberations of a body like the Advocacy Commission.

The truth of the matter is that my mother had only a fleeting notion of what Alzheimer's was, and never really understood that she had it. Throughout her illness she would ask me, "What did you say it was again?" When I had finished telling her that it was Alzheimer's and explaining it for the hundredth time, she would nod cheerfully and venture what became her perennial last word on this matter, "I suppose it's just old age."

The first section of the Advocacy Act speaks of the empowerment of vulnerable people but does not explain how one can safely empower the incapable. No one could fault the bill's desire "to promote respect for their rights, freedoms, autonomy and dignity," but in the case of Alzheimer's patients, the intrusion of an expensive, potentially inexpert and slow-moving bureaucracy between those who have the illness and the family members and doctors who look after them threatens to be self-defeating. Such a bureaucracy seems much more likely to diminish their rights, freedoms, autonomy and dignity than enhance them.

How could advocacy services, in the words of the bill, help Alzheimer's patients "make their own decisions, exercise their rights, speak on their own behalf, engage in mutual aid and form organizations to advance their interests"?

The more one reads the legislation, the more obvious it becomes that it was written with other illnesses or disabilities in mind, or was at the very least written by people who had no experience with Alzheimer's. As far as we of the Alzheimer association are concerned, Bill 74 is a square peg being jammed into a round hole.

When you add to the bill's inappropriateness for Alzheimer's patients the draconian powers it gives advocates to enter premises on suspicion and without a warrant, to meet vulnerable persons privately and to gain access to any document or records, it becomes, quite simply, intolerable.

Bill 108 on substitute decision-making, although I see it as less of a problem in some ways than Bill 74, is also disturbing in that after incapability has been declared—that is subsection 16(5)—advocates are still required to meet the patients formally, notify them of and explain to them the significance and effect of the incapacity certificate, explain their rights to refuse the statutory guardianship of property, and then ask them whether or not they want to refuse it.

Alzheimer's patients are very often good actors and actresses. I can recall meetings with old friends of the family at which mother behaved charmingly, listened politely, made conversation and generally gave the impression that she was glad to see them all again. On the way out they would say to me, "She seems fine, just like her old self," or words to that effect, and perhaps even look at me strangely, as if I had exaggerated her incapacity. When they had gone, a puzzled frown would return to mother's face and she would say, "Who were those people anyway?"

The point is that in those circumstances she would say what she was astute enough to realize people wanted to hear. In other circumstances later in her illness she could be quite negative. She would say no to any question or any suggestion. If you asked whether she had eaten, for example, she would be quite capable of saying that she had not had anything all day even if she had had a good lunch 10 minutes earlier.

So unless the advocate, or any other intervenor on behalf of the disabled person, knows a good deal about the nature of the illness, the results of interviews and cursory investigations could be very misleading. There is no assurance in the legislation, at least that I can find, that the advocates will have the necessary medical training.

It is very difficult to establish the capability of an Alzheimer's sufferer, it seems to me, because in my experience clarity of thought and memory can be like a loose electrical connection, unreliable and intermittent. When mother was still living with us, and before we realized how deeply Alzheimer's had affected her, it became apparent that one section of her very modest will which mentioned specific stocks and numbers of shares had been overtaken by events. There had been a three-for-one stock split since the will was written. This left two thirds of her holdings unassigned. Since mother had clearly intended to divide

the stock in question between two people—I was neither one of them, incidentally—I thought it would be better, as the executor, if the will was changed to reflect the new situation.

I called my lawyer, explained things to him, and he came out to the house as a witness. My wife and I, as interested parties, were barred from the room and the usual legal test for competence was given. My lawyer and his colleague came back to us after a while and informed us that in their view mother was perfectly capable of making changes to her will. The problem was, when we asked her about it later, the change she favoured was to give all of her stock to me. She had forgotten her original intention, one I was certain that in normal circumstances she would not have dreamed of changing. She was not capable, in other words. In the end, as the lesser of two evils, we decided to leave the will alone.

There is nothing in Bill 108 which convinces me that the measures it proposes for substitute decision-making would be particularly appropriate for Alzheimer's patients.

I have even more problems with Bill 109, An Act respecting Consent to Treatment. Under section 16, unless I had previously been established as mother's attorney for personal care purposes, I would have been number five on the list of people whose consent would be sought in the event some change was needed in mother's treatment.

In my view, and in the view of the association, the list is backwards. It should begin with the person who has been given power of attorney, usually a family member, and should progress through other relatives to the public guardians. Being elbowed out of the decision-making process in this way suggests that, by and large, family members are not to be trusted. People have rebelled for smaller abuses of their rights than that.

My mother had all kinds of medical problems in addition to Alzheimer's. She had arthritis most of her life. Towards the end she developed congestive heart failure. She had problems with her eyes and with her teeth and wanted nothing to do with eye doctors or dentists. She fell five times in her declining years, breaking her pelvis twice, her hips twice and cracking her spine once because the arthritis had left her weak and unsteady on her feet.

What if Bill 109 had become law before mother died and she had fallen and broken her arm, cracked her rib, cut or burned herself, or had done herself some other injury not likely to cause her, as the act puts it, "serious bodily harm within 12 hours" if it were not treated promptly? And what if in her pain and confusion she refused treatment, as in fact she always did?

If Bill 109 were in effect and the doctor had reason to believe mother was not capable, his hands would be tied by her refusal of treatment. The professional advocate would have to be summoned to convey mother's wishes to the doctor and to explain to her that the doctor's decision to start treatment could be appealed. The advocate's explanation would be sufficient, the act suggests in subsection 10(2), even if mother did not understand it.

If mother decided to appeal, the advocate would have to bring in a lawyer. The case would then go to a review board, which could be held up to seven days later, where a

panel would decide if mother were competent. Even if she were deemed incompetent, as seems probable but not certain, the advocate would then have to explain to her that she could appeal the panel's ruling. If she decided to do that, no medical treatment could be given until a final decision was handed down.

No son worthy of the name, or doctor worthy of his oath, it seems to me, would submit meekly to this kind of rigmarole if an incapable mother or patient were in pain, and so the temptation to break the law and take our chances would be very strong.

#### 1550

I put it to you that in the case of Alzheimer's patients, the legislation is not only ridiculous but, because it fails to protect patients from their own dementia, it would, if adopted, tend to put them at an even greater disadvantage than they are now. We are also dismayed by subsection 15(1) of the bill designed to forbid invasive procedures on incapable persons when the primary purpose of such procedures is research. The association is afraid that this might prevent persons with Alzheimer's from participating in drug trials which could one day be of significant benefit to them and their fellow sufferers. For heaven's sake, let's rethink that part of the legislation as well.

In closing, I would like to read you an excerpt from an article in *The Observer*, July 7, 1991, by a much better writer than I am, Michael Ignatieff. He lives in England now, but his father, George, was a distinguished Canadian public servant. Mr Ignatieff speaks feelingly on the subject of Alzheimer's because there have been three generations of the disease in his own family.

"The carer's burden," he writes in *The Observer*, "is not just a matter of making sure that patients don't wander, don't leave the gas on, get properly washed and put to bed. It's also the strain of repeating the same thing a thousand times, of trying to make contact with those vacant, unfocused eyes. Carers have needs too and yet only the sufferer's needs are met.

"What care givers need above all else is a respite. Caring for Alzheimer's patients can kill you. There should be day care and residential centres as well as a domiciliary nursing network so that primary care givers can get away for a break.

"At the next election, when we get our regular doses of rhetoric from politicians of all parties about the importance of family life, we should be ready with one question: Are you in favour of respite care for families who care for the demented and the disabled?"

Not a bad question in my view, even in Canada, and it suggests what might be a more productive way of spending \$20 million to help promote respect for the rights, freedoms and dignity of Ontario's disabled. Surely helping people and their families to help themselves would be more useful in the long run than creating more intrusive bureaucracy; and it would do something more than pay lip-service to the pious hope contained in clause 1(f) of Bill 74 that the legislation should "acknowledge, encourage and enhance individual, family and community support for the security and wellbeing of vulnerable persons."

Thank you very much.

**The Chair:** Thank you. Each caucus has about two minutes for questions and comments. Mrs Sullivan.

**Mrs Sullivan:** Thank you very much. That was, I would say, a very impressive, articulate brief, speaking particularly about the special nature of Alzheimer's. In fact, many of the things you talk about move over into other areas of illness and disease, and I am thinking particularly of stroke, in which many of these similar circumstances exist and so on.

I was interested that your recommendation is to abandon Bill 74 and revise Bills 108 and 109. My impression is that you see substantial revision required to Bills 108 and 109 for them to be acceptable. Our position has been that since these bills were put forward as a package, they should be withdrawn and redrafted as a package. I wonder if you would comment on that potential situation and if you see a place, for example, for advocates in situations where there are no family or friends as care givers.

**Mr Trueman:** I think my colleagues have thought more carefully and in more detail about the legislation in that respect, and perhaps they would like to answer that question.

**Mr Ellis:** You are right. We have similar views on this. Our idea is that Bills 108 and 109 would require revision if you abandoned the Advocacy Act, so if we take away the role of the advocates as it is envisaged in the legislation, that will automatically require revision in those two other bills. However, the concept of power of attorney for personal care, for instance, is something that we can support. They have to be simplified, though, and cleaned up a lot.

**Mrs Sullivan:** Have I got half a second left?

**The Chair:** Actually, 30 seconds.

**Mrs Sullivan:** Okay. Then where that leads is to the next question regarding the usefulness of advocates or the expansion of funding or services through existing agencies in order to provide services to people who do not have family and friends or an advocacy agency such as the Alzheimer association, where indeed there may be some assistance to ensure accountability and, I suppose, individual authority, autonomy in decision-making to people who do not have supportive assistance.

**Mr Trueman:** There is no question that people who do not have anyone to speak for them need someone to speak for them. We are talking here, though, about the vast majority of individuals who have Alzheimer's disease and do have personal care givers with them. I think it is important to focus on that group and not get diverted. This seems to be part of the problem with the legislation. A very small minority of individuals have been catered to, in a sense, and a whole system of legislation built around them. When you are developing legislation, I think it is time to stop asking about the very small number of people and focus on the kind of legislation that is going to be beneficial for the large majority of people.

There is potentially a role for a small number of advocates, yes, for those individuals who have no one to speak for them, and I think our position is fairly clear that there are vulnerable people who require some assistance in that

regard. But when it comes to drafting legislation that affects such a broad population as this, we want to focus in on the large majority of people.

**Mr Sterling:** I do not know if you recall that when I was secretary for justice, I worked very closely with the Alzheimer society. I was basically the instigator of the durable power of attorney dealing with property. Up to that time, a person could not make a power of attorney past the time of competence to incompetence, and had to go through a court procedure. I have gone through an experience not unlike Mr Trueman's in terms of dealing with a parent who was suffering from this very debilitating disease, so I understand, to a very great degree, your experiences, Mr Trueman.

I am not willing at this time to say, "Do away with Bill 74." I just find Bill 74 such a bare skeleton in terms of what these advocates are going to do, what their training is going to be, and particularly their interrelationship with the other advocates, and primarily the advocates that most of us know, and that is the family members. There is no relationship between the professional advocate and how that advocate interrelates with the family. When does that professional advocate step out of the situation and the family one walk in? The reason I would say "Junk Bill 74" is because I believe that there has not been enough thought about how these people are really going to function when they are out there. I think the people who are supporting them have a very different idea of what the role of the advocate is, versus the people who perhaps drafted this piece of legislation.

At any rate, let me ask you a specific question about the consent procedures in this act. I think the government has laid itself bare to significant criticism, which it received this morning from a joint coalition that basically said, "Junk all of the legislation," by not bringing forward amendments, as it was recognized that there were real problems with the legislation. One of the suggestions I have heard, in terms of the consent, is that you would not necessarily call an advocate in unless the incompetent person requested that advocate. In other words, the first question to the incompetent person would be by the health care provider, perhaps: "Do you want an advocate to come in and talk to you?" Would that remedy your concerns with regard to the consent procedure?

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**Mr Trueman:** Speaking from my own experience, it would have left mother absolutely cold. She would not have known how to handle that. It would of necessity have to be a leading question, and she could respond one of two ways depending on her mood on that particular day: She would flatly say no or she would say—but she would not understand what it was all about in the latter stages of her illness.

**Mr Sterling:** I do not want to use your experience, Mr Trueman, because I know your motives were correct, but how would you protect a mother who was perhaps not being treated as well by her family as we demand in society?

**Mr Trueman:** I am not sure about that. Do you have ideas about that? We admit the need, as we said throughout.

**Mr Sterling:** Because of the frustrations of Alzheimer's, it is not without the possibility of thinking of abuse of the Alzheimer's patient.

**Mr Trueman:** I know, but look, we are talking about 120,000 people in Ontario. You go through that legislation as I tried to from the start; even the preambular sections obviously do not fit and do not apply to Alzheimer's patients. You go through all of Bill 74 with Alzheimer's people in mind and rewrite it, then perhaps something might come of it. But how many people does this piece of legislation affect? It cannot be, what, 200,000, 300,000, 400,000? If it simply does not apply to 120,000 of them at all, surely that is reason for doing something to change it.

**Ms Carter:** Just to pick you up on that point, this act cannot apply to everybody, and it seems to me that Alzheimer's patients who, as Mrs Sullivan said, are looked after by family and friends and so on, or who are so incapable that they cannot express really meant opinions, are not within the territory of this act. I do not see that as a problem. It deals with the people who do come within its territory. In other words—

**Mr Trueman:** But you interpose between people who have good and competent care givers and the patients; you impose a new level of bureaucracy.

**Ms Carter:** I guess what we are saying is that is not intended to be the case. The Advocacy Act would apply only in the case of people who do not have that and only, again, if they are capable to some degree of expressing their opinions.

**Mr Trueman:** But no such exemption is made in the bill.

**Ms Carter:** Okay, I have taken that point, but I want to raise another point. You mentioned the unsuitability of Alzheimer's patients to be on the commission and I think that is correct, that neither the victims themselves nor the families are actually likely to become members of the commission.

The intent of the act is to keep the commission consumer-controlled and obviously that has to be limited to those people who come within the category of consumer but who are capable of performing that kind of function. That does not mean there will not be a role for care givers and others as advisers, and certainly expertise and advice from those people who will be listened to, particularly regarding education and training of advocates, that kind of thing.

You may notice also that under section 15 seniors are given as a group that will be represented on the—

**Mr Trueman:** Commission.

**Ms Carter:** Well, this is the group that is going to select the commission. It is one stage removed. That is people representing persons 65 years of age or over, and it seems to me that category is quite likely to take a particular interest in Alzheimer's because, after all, they themselves run a very large future risk of getting it, and—

**Mr Trueman:** Since women, too, are so overwhelmingly designated as care givers, I would think the women's movement would be extremely interested in this as well.

**Ms Carter:** Yes, but then, of course, these categories do not exclude that in any way, and given that more women maybe survive some of these things they would tend to be more represented anyway. Do you not agree that seniors might—

**Mr Trueman:** Yes, I think they would have a special understanding of the illness, more so than the younger among us.

**Mr Ellis:** However, I do not think it would be wise to base legislation on the assumption that because certain people might end up getting Alzheimer's disease they have a special insight into the role of such a commission. The overall view we have is that we are afraid that when you get advocates out there, who in this legislation really have considerable power, without the kind of understanding required to deal with situations such as Peter has been describing with his own mom, you run into very risky situations.

**The Chair:** Mr Gay, Mr Ellis and Mr Trueman, on behalf of this committee, I would like to thank you for taking the time out to come and give us your presentation today.

JO PETERSON

**The Chair:** I would like to call our next presenter, Mrs Jo Peterson. You will be given a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. Would you please identify yourself for the record, and then proceed.

**Mrs Peterson:** I am Mrs Jo Peterson. I am from Hamilton, Ontario. I am a family member and a member of the Hamilton chapter of the Ontario Friends of Schizophrenics. It is my intention this afternoon to tell you my personal story, and then to read to you what I see as the weaknesses and strengths in the acts, and to give you a summation of same. I understand I have 30 minutes for this presentation and I will do my best to get it within that time limit.

I am concerned that the difficulties we encountered in seeking help for our daughter will be further compounded by the introduction of the proposed legislation. We see our family as being a pretty normal family. I have been married to the same man for 40 years and have three children. All my children were considered to be intellectually above average. Our youngest daughter was considered to be the brightest. All three attended university. Two graduated with degrees. Our youngest daughter did not graduate because she developed an illness that is known as schizophrenia.

When we know what we know now, we can look back and see some changes in her behaviour as early as grade 12. She was withdrawing a bit from the family circle. There was some lack of concentration, and there was some use of foul language. At her graduation party, which we orchestrated for 20 people, two turned up. We were puzzled and we questioned her about this. She was very vague. She said the kids did not like her, the teachers were

tough on her. When we asked the two students who attended, they said: "She's a loner. She's extremely bright. The kids don't like somebody who's extremely bright, and maybe your party was the last on the list and they didn't have time to attend." Well, I knew that was incorrect, because all kids go to all parties and try to take in as much as possible.

When she went into grade 13 she was saying the same things about the students and the teachers at school, but she changed her schooling three times during that year, and we questioned that. Once it was with our permission, twice without. Again she said the teachers were not understanding her clearly. When I approached a teacher about this, he said to me: "You have an extremely bright child. She writes with great spurts of brilliance. Kids don't seem to like people in that group."

He showed me an essay she had written. She got A-plus, and he wrote on that, "signs of brilliance." But did he read it? I questioned that. I questioned our school system and I questioned his care for his student, because there were jumbled thoughts within the essay. I asked him about that, and he said, "Your daughter said she was thinking of some other things and just jotted them down and forgot to erase them." I saw those remarks as something that was mind-altering, and what I want to tell you here very clearly is that schizophrenia is a mind-altering illness and that should not be overlooked.

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She went on to university, naturally, because she was an honour student and several universities wanted her to attend. She selected one quite a distance from home, and it was not too long before we were getting letters from her with envelopes that contained religious notations. I am not going to try to tell you that we are overly religious, because we are not, and we wondered about that. She was saying the same things about her professors and the students that she had said in the past, but now she was saying that kids were jumping out of her locker, hiding under her bed, and that somebody was talking to her but they were never there. It did not take us too long to realize that she was hearing voices.

We went down to the university because she called one evening and said, "I just smashed a mirror and I want to kill myself." When we went down we interviewed some of the students, and they said: "Your daughter is not a person who attends the pub. She's not into the drug scene and she's certainly not into the sex scene. She's definitely a loner—very, very intelligent, maybe a little eccentric."

When I talked to the dean, he said: "She's very intelligent, probably eccentric. Kids, we are told, tend to stay away from the bright ones—first time away from home, having trouble settling in." We wondered.

We tried to get her to come home. She refused. She said, "Next year, I will go to another university closer to home." She did very poorly—a wasted year. She talked at the other new university about kids again hiding in her room, someone talking to her, but now they were tormenting her. But there was nobody there. She started to talk back to these voices.

At the year-end we talked her into staying home so we could observe her more closely in trying to find some answers to what was happening. It was not too long before we saw some very strange behaviour because now she was in the relaxed atmosphere of the home. When she was at university, she was able to mask some of those feelings and pull herself together enough to be elected as secretary of the student body—and that is another thing: When police are called to crises in homes, sometimes the person who has the illness can mask those feelings, can pull it together and the scene is not the same and so therefore there is no help.

What I noticed was that if I was walking anywhere in the house or on the street and I turned quickly, we would be face to face, almost noses touching. If I got in the car, she got in the car with me. If we went out for an evening, she phoned several times. She became very suspicious of my actions and she accused me of things that I would never think of doing. Then she decided to tell the neighbours and it became more embarrassing—one time running down the street screaming. We did not know what to do. We called a psychiatrist friend, and he said: "She probably thinks you're more ill than she is. You're not going to get help. Have you read the act? The act clearly says, unless she is a danger to herself or to someone else you haven't got a hope in hell in getting help for her." We thought about this and found it very difficult to believe.

One night we were awakened by horrible screams and rushed into her room. We did not see a young woman. What we saw was a small frightened child in a corner of the bed in a foetal position screaming that animals and snakes were crawling all over her and asking us to get them off her. The look in her eyes was one that I will never forget, and when I reached out for her the fear from her body generated through mine. It was an experience that I shall never, ever forget.

The next morning I called the psychiatrist friend and told him what was happening, and he said: "Your daughter has some kind of brain disorder. Schizo-affective maybe, maybe manic-depressive, could be schizophrenia. But," he said, "you're not going to get help. Is she violent?" I said no. "Has she hurt you?" "No." "Has she hurt herself?" "No." He said, "Then you can't get her into the hospital because she's not a danger to herself or to you. But," he said, "she'll probably become suicidal, and all I can say to you is good luck and I'm sorry."

I looked at my husband and he was totally devastated, and I wondered what this would do to him, because I am the much tougher one in the family. My husband travelled a lot and I had the children to cope with more than he did. We thought the only thing we could do is to wait and see what happened. But we did talk her into going to see our family physician, and he said, "You're very depressed, and it's a good thing you're not going back to school and are staying in your home." When she came home and said, "I'm depressed," I looked at my husband and said: "Is this the way depressed people act? I hardly think so." So we watched and we watched and we waited, and after a few months my husband could not stand this any longer and he

said, "We'll have to take her to the hospital, and somehow we have to get help."

Well, I am sorry to say that we literally threw her into the car. We struggled, almost having an accident getting to the hospital, and when she realized what we were doing, she became very frightened. We explained to her, "We're not having you committed; we're trying to seek help for you."

When we got to the hospital, to get her into the hospital we had to drag her by her hands and feet across the floor of the garage until we could get some assistance. Needless to say, when we got into the doctor's office, we were taken first, because the office cleared out.

They brought down a psychiatric team to look at her and they said: "She's not a danger to herself. She's not a danger to you. There's nothing much we can do for her and she seems competent." Competent? What does the word "competent" mean? "Competent" seems to mean so much to different people. We saw her as not competent; they saw her as competent. The act has to clearly define the word "competent." I have some tough times thinking about how advocates will define "competent."

We stood there, and all we could do was hope and pray that she would say in public, to the doctors, what she had said to us, and finally she did: "I would like to kill myself," and within two seconds she was being admitted.

We left the hospital thinking, "What kind of system are we putting her into?" If you are physically disabled, you walk down a hall and people open the doors and beckon you in, because they have got the goodies for you, but if you have a mental disability, you walk down the hall and you do not get in the door, they shut it in your face.

I thought: "This is my country, Canada. I am a taxpayer. This is my province, Ontario. They say they offer universal health care of the best quality to all Canadians. Aha, but I didn't read the small print: 'Except if you have schizophrenia.'" We have the smallest amount of money going to research for this illness, and if you have something wrong with you and you are running around like a crazy person, you have to be a danger to yourself or to somebody else. Is that the best health care? I do not think so.

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I would like to touch on some other concerns our family have for our daughter. She is fairly attractive and she wants to be loved and she wants to be taken care of by someone other than her family, like a man, a lover, a husband. Oh yes, she meets men, and she meets a lot of them. She is very vulnerable to men, and the word "vulnerable" in the act has to be clearly defined. We are worried about her wellbeing and her safety. She meets men of the worst type. They take her money, they move into her apartment and they start to control her. Now we not only have to worry about her mental wellbeing, but we have the AIDS concern. She never smoked before she became ill, and at one time she was smoking two and a half to three packs of cigarettes a day. What happens when these men come into her life and start controlling her? It is relapse after relapse, and we start all over again trying to get her hospitalized. Each time we see her deteriorate more, and each time we

are told the same thing: "She is competent. She is not a danger to herself and she is not a danger to anybody else."

Two years ago, because she would not take her medication, I told her I would not take her on vacation because I was taking the grandchildren and it would be too hard on them. She seemed to understand that, but one wonders when they nod their heads. Would they nod their heads to almost anything you ask? I really do not think she comprehended what I was saying. Obviously not; she hitchhiked up there that night, in the middle of the night, and was picked up by the police, who had her hospitalized. When we found out about this I got in the car and drove around the area where she had been picked up. It was pitch black. There were very few cars on the road. I was relieved that she had not been raped, murdered, robbed or God knows what.

Last year it was the same thing, only this time she behaved a little differently. She is not a violent person. She heaved a brick through one of our windows. When on medication, my daughter is a very warm, loving, kind, generous person and a very supportive person. But when she is not on medication she is abusive, she is abused by men and she torments all of the family. She torments all of the family because she hears the voices. She was able to live in her own apartment for three years, but because the voices got out of hand when she went off her medication, she wanted to throw herself off the balcony. She would not return to her apartment.

So where does this really leave all of us? It leaves her rights intact, there is no doubt about that, but her needs certainly are not met. I often wonder: If her needs were met, would the rights be such an important issue?

Let's look at rights. We all have rights. I do not think you are probably too interested in my rights, but I have the right, because of the Mental Health Act, to watch my daughter deteriorate from somebody who was considered brilliant to somebody who now sits around doing very little, smoking, and being abused by men. I have the right to watch my husband cry every evening after she leaves our home. She has been ill for 14 years. I have the right to watch my friends and neighbours question why we cannot get help for her: "What is wrong with us?" It is not us. It is definitely not us. I have the right to come in conflict with our community, health professionals and politicians. I say to you, do I want to come in conflict with these people? Most certainly not.

I am not your enemy. Families of people who are ill are not your enemy. We are trying to be your ally. All we are asking is to be listened to.

I think advocacy is a great thing. I spend a lot of time working out there for schizophrenia. I think advocacy is very good for those who are going to be abused or neglected and who do not have people to assist them, such as strong family ties or friends. But really, who better to advocate for my daughter than her family? We know her best and only want to act in her best interests. We will do it for as long as we are on this earth and she is here. I would have some concerns about a bureaucracy being able to be sensitive to the needs of our people.

You know, Nancy B. fought for the right to die. My relatives and the relatives of the families I know want to get on with their lives. They want to find someone to share it with. But they have been murdered, and they will murder. They have been robbed, and they will rob. They have been abused emotionally, physically and sexually, and sad to say, they are looked upon as second-class citizens in this wonderful country of ours. They do not have to go to court for their rights like Nancy B. This system gave them the right to a slow death. There is only one difference: They have to keep those rights on to have it. I think that is wrong, and I think it is sad.

I would like to read to you what I see as the strengths and weaknesses in the acts.

The Advocacy Act: I think one of the strengths is to increase the voice of the consumer and to formalize advocacy service for those who, because of their illness, may be targets of abuse or neglect. I see weaknesses as to what is meant by "vulnerable." There has to be a clearer definition. There is no focus on the needs; just rights. Not everyone who has survived mental illness can speak for others and their needs. This seems to be assumed. Where is the representation of family care givers and professionals in choosing members of the Advocacy Commission?

You have a wealth of knowledge. When we first came into this system I can remember a nurse saying to me, "I want to introduce you to a group known as the Ontario Friends of Schizophrenics, who will help you understand the illness and help you with coping skills, because they know what is needed in this province of ours," and that is exactly true. Here you have a wealth of knowledge, and it is not being used in any way, and I think it is disgusting that members who are care givers and have this knowledge are not members of some kind of commission or board to these acts. Why is it that schizophrenia was not included in the exception given to groups representing neurological disorders such as Alzheimer's? It is my belief that people with chronic schizophrenia are unable to speak for themselves as well.

Bill 100: The strengths of the act: the recognition that one's capacity to make decisions may be partial and may fluctuate. The wishes of capable people, even if they become incapacitated, are supported. Weaknesses: What is meant by "competence"? It is not clear. What determines competence? It is not clear. The advocate's role in determining competence? Not clear.

Bill 109: Families unclear of their role and assuming advocates would take over where there is family: this has to be made clearer. There is a real misunderstanding of that among families, and it is distressing and causing them more stresses. A very complicated array of procedures protecting the rights of persons wishing to refuse treatment; no support that treatment restores competency and autonomy in some cases.

These bills lead to dissatisfaction, distress and demoralization for those with this illness.

Bills 108, 109 and 110: No clear definition of competence. The qualifications of the advocates? Not clear. Treatment delays will be increased, and there cannot be delays for treatment. It should be immediately. Committal

laws still will be unchanged. There is a poor understanding of the nature of schizophrenia and other severe mental illnesses as to the biopsychosocial nature of illnesses.

There is no guarantee of speedy action. This is only going to increase the burden to the family and the care giver. There is a real need to look at connecting rights and care. We all have to recognize reform is needed, but not what has been proposed. I really feel these bills have to be reconsidered.

**The Chair:** Thank you, Mrs Peterson. On behalf of this committee I would like to thank you for taking the time out today and coming and giving us your presentation.

1630

#### ONTARIO NURSES' ASSOCIATION

**The Chair:** I would like to call forward our next presenters, from the Ontario Nurses' Association. Good afternoon. Just a reminder that you have a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments. As soon as you are comfortable, could you please identify yourself for the record and then proceed?

**Ms Christianson:** Good afternoon. My name is Mary Jane Christianson and I am the president of the Ontario Nurses' Association, the trade union which represents 55,000 staff nurses in this province. With me today are Glenna Cole Slattery, chief executive officer; Noelle Andrews, associate director, government relations; Lesley Bell, assistant director of government relations, and Carol Helmstadter, research officer, all of whom are registered nurses.

As the voice of the staff nurses working in hospitals, community health, industry, nursing homes and homes for the aged, we bring a unique perspective to the issues addressed in these proposed pieces of legislation. Staff nurses are the primary support for the security and wellbeing of people with mental and physical disabilities, illnesses and infirmities. No one is more aware than we are of the need to treat these people with dignity and respect, and to allow them to make their own choices as much as possible.

The government is to be commended for the introduction of the legislation covering consent to treatment, substitute decisions, and advocacy. We agree with the principles contained in the government's initiatives. One cannot argue with the overriding principles of protecting the physically or mentally impaired, nor can one argue with the principles governing informed consent to treatment and no treatment without consent. We also recognize the need for advocates and substitute decision-makers in the delivery of health care.

Having said that, we have major concerns, both as consumers and as health care providers, with the way in which these principles are being applied. The fundamental areas to be addressed by these bills are mental competency and the role of the advocate. They are not clearly defined by the proposed bills. Rather, the government intends to address the very heart of its initiative through regulation. This union does not believe the regulatory process is the

appropriate forum to be addressing the essential elements of the proposed acts.

Looking at mental competency first, the existing bill, the Consent to Treatment Act, Bill 109, directs the health practitioner to apply prescribed criteria and follow prescribed standards and procedures to determine the capacity of the individual with respect to treatment. The prescribed criteria, procedures and standards, however, are not contained in these bills and therefore are not open to the necessary consultation of determining such important directives.

Second, looking at the role of the advocate, staff nurses have traditionally been advocates in conjunction with family, clergy etc. This government seems to see these traditional advocates as adversaries and therefore proposes another administrative commission, the Advocacy Commission. The commission will determine (a) minimum qualifications and educational standards for advocates, (b) the mechanisms for providing advocacy services, and (c) guidelines for determining mental capacity.

These are the very questions that we believe the bill was designed to address. In their absence, the proposed bill is meaningless and the government is delegating its elected responsibility to an appointed body.

A third concern is the cost of establishing this advocacy system. Health care is not confined to the institution, nor is it confined to the hours of 9 am to 5 pm. Health care is delivered in all settings, 24 hours per day, 7 days per week. Has this government given any consideration to the number of advocates which would be required just to cover the number of institutions in the province, not to mention the sheer geography of this province?

Moving away from the underlying principles of the proposed bills, we will address the omissions to the proposals. "Treatment" is currently defined as "anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose and includes a course of treatment." This definition is far too broad and all-encompassing. We recommend that the current definition be specific to major treatments and it be the responsibility of the individual who prescribes a treatment to obtain the necessary consents, not the practitioner delivering the hands-on care.

The Advocacy Act must explicitly include protection for health care workers who work with vulnerable people from proceedings for damages, just as it already protects persons working for the Advocacy Commission or in community programs.

In the interests of the people whom we serve, the creation of a positive environment secure from frivolous and vexatious complaints must be present to enable the staff nurse to deliver the necessities of care. Staff nurses are constantly faced with the double-jeopardy situation. We are professionally accountable to our regulatory body, the College of Nurses of Ontario, and as employees to our employer. This is quite different from the situation of other regulated health professionals such as physicians, who are regulated private entrepreneurs. In our brief we have outlined suggested wording: "No proceedings for damages shall be instituted against a health practitioner for any act

done in good faith in the execution or intended execution of the person's duty or for any alleged neglect or default in the execution in good faith of the person's duty," and it is on page 4.

In addition, there should be a clause requiring each agency providing service to establish clear policies for dealing with such complaints. We are extremely anxious that the basic aim of the advocates should be to understand and to seek to improve the quality of life and the care of vulnerable individuals. Complaints should not be directed against individual care providers but rather aimed at the activities of the facility as a whole.

We believe that it is in the interests of both the vulnerable people being served and the health professional providing care to work towards continuous improvement of the facility's structure and practice so that everyone, the health care team and the clients, can benefit. We strongly recommend that appointments to both the advisory committee and the Advocacy Commission include a registered staff nurse. It is the staff nurse, after all, who delivers by far the greatest amount of hands-on care to these individuals. She is, therefore, the most suitable health professional to provide firsthand information and education.

In addition, we recommend the establishment of a legislated bipartite advocacy committee modeled on the occupational health and safety committee. The mandate of this committee would be to resolve problems in the best interests of the clients rather than to lay blame and to impose discipline on individual practitioners.

In closing, this government must ensure that the proposed initiatives will not lead to unnecessary delays or confusion in delivering essential health care to the citizens of Ontario. We thank you for your attention and would be pleased to clarify any points or respond to questions.

1640

**Ms Cole Slattery:** I would like to put a codicil to the president's remarks. I am trying to think of a word that is stronger than "adamant" and I cannot, but our point we make that we could not make forcibly enough is the point that relates to the enabling legislation, which must carry the legislative intent, and that the regulatory procedure be used only for the regulation of what the elected officials of government believe to be the proper enabling legislation.

We have had now since 1989 absolutely one of the most dreadful experiences of any group I know of in North America with the regulatory process, that being the paucity of the fulfilment of the Minister of Health's intent when she regulated the Public Hospitals Act and allowed registered nurses who worked at the staff nurse level access to hospital committees on decision-making, planning, operational and fiscal oversight. We are conspicuous in our absence within the hospitals of Ontario, who have blatantly refused to follow what I consider to be an attachment to the law of the land, that being a duly authorized and executed regulation to a standing act.

We anticipate that if the government does not take a very firm hand and legislate what it believes must be done for the citizens of this province who will access this piece of enabling legislation, it will lose its right, and I personally

suggest that it will have abrogated its responsibilities in turning this over to the bureaucrats who structure the regulatory process.

We are absolutely and totally disillusioned with our experience, which was meant to be a positive one, under the old Public Hospitals Act. We cannot underscore enough our concern for the consumer, the potential patient and the staff nurse who will deal with that. But more than that—if there could be something more than that—it is the right of a seated government and the responsibility of a seated government to legislate and not leave it in the hands of those who draft regulations.

Noelle, having had a bit of involvement with this, has a comment as well.

**Ms Andrews:** The other area we want to underscore and bring to the forefront, in case it gets lost, is the whole area of consent to treatment. As a profession, under the Regulated Health Professions Act and its revisions we were stopped from prescribing treatment. We have major difficulties if as a profession we are now in fact going to be obliged under this piece of legislation to carry out the actual consent to treatment, explaining the treatments, and all of the functions that go with that. We have major difficulties the way it sits now. It will fall on the registered nurse to obtain the consents, even though we were disallowed under a very recent piece of legislation from prescribing treatment.

Taking that one step further, in terms of liability as it relates to the staff nurse, we simply would have no option other than to advise our members not to (a) obtain those consents, or (b) carry out any treatment in the absence of a consent.

The "treatment" definition is very broad. It could be as simple as getting foot care completed, and in fact you would end up having to have a consent drawn up for that procedure. We just cannot emphasize enough the importance of the definition of treatment and who it is that will be obliged to obtain those consents.

**Ms Cole Slattery:** Our feeling is that if the consent to be obtained was not for foot care, for instance, but was indeed for electroshock therapy, then that is between the patient and the patient's husband, wife or family, because there are residuals to that treatment. There have been known cases where it was not the treatment of choice but the treatment of the prescriber. Those are two entirely different things, from time to time.

What we are telling you is, the way it is structured now, you put 55,000 staff nurses in this province who might work in mental health or in psychiatry under these bills in incredible jeopardy. We as a union would encourage them not to work there. We are not indentured servants; we do still have that small choice.

**The Chair:** Thank you. Each caucus will have about five minutes for questions and comments.

**Mrs Sullivan:** I think one of the things you will be interested in knowing is that this morning a coalition of groups and agencies, from the hospital association to the medical association, various advocacy groups and organizations which are made up of people who deal with and

work with people with specific illnesses, including the Friends of Schizophrenics, appeared before the committee and suggested that these bills be withdrawn and that these hearings be used as a consultative phase, given the lack of consultation leading up to the introductions of these bills, and that a redraft of the bills be done to make them more accessible and amenable, not only to the health care providers but to the consumers as well. That has been my point of view for a long time. I wonder if you would like to comment on that kind of proposal.

We are naturally concerned about the vague notion of advocacy you have alluded to, that the definition of advocacy would be left to regulation process, that the collectivity of the bills would in fact provide an obstruction to the care of patients rather than enlarge the patients' rights or indeed provide them with rational and appropriate health care at the time.

You have mentioned the paramountcy of obtaining consent, and you may want to talk about that. I am not sure how much time of my five minutes you are going to have left, but I would be very interested in hearing your views on what you think about a redraft of these bills. It seems to me that is the way to go.

**Ms Cole Slattery:** We would be 100% in favour of that. There is a brief period of time here with which to share our views with you. Others have every right to come before you and speak about what they consider to be critical to the issue at hand. We believe that this is a legitimate government business, that this is a legitimate piece of enabling legislation. It certainly needs review. It needs to be hammered out, and it needs more than could be done to modify it or improve it in its present form. We would wholeheartedly support and urge the seated government to give thought to a proposal of withdrawing these bills, but not withdrawing the philosophy or the intent to legislate in this area.

**Mrs Sullivan:** Thank you. Would you like to continue on the paramountcy of consent? I think that is a matter of some importance relating to the definition of treatment and course of treatment, but indeed how a working staff nurse would see the consent legislation as it is now drafted affecting the way she would deliver service on the floor.

**Ms Cole Slattery:** There is a word that needs to be put in before the word "consent" when you talk about consent in any fashion, and that word is "informed." I believe there is an obligation that it is an informed consent, and if a patient is almost mentally obliterated by the agony or the terror of what is going on in his life at this time—for instance, in traumatic automobile accidents, people are being asked to consent to things for which all they would say if you said, "I'm the physician and I want to cut your leg off," would be, "Okay." The patient is not usually going to say: "What? How come you want to cut my leg off?" The permission to perform a service or a function on another human body, if the physician says, "I'm going to have to cut your leg off; your arteries are mangled and you will bleed to death," is different. As a staff nurse, I resented physicians who had people on the operating room schedule for the next morning and when I went in to explain the

procedure to them, I found out there was no consent and I would call the physician and say, "Tell them what a gall bladder operation is."

1650

**Mrs Sullivan:** I think you are going in a different direction from the question I was asking.

**Ms Cole Slattery:** No, I am going to say that whoever gets the consent, two things should be present. The person who is going to be the recipient of the treatment must be informed of the treatment, why it needs to be done, what the downside is of doing it and what the downside is of not doing it. That must be done by the person who is legally authorized under other pieces of enabling legislation to perform that procedure. If I said to you, "In my estimation, you should have your gall bladder removed, and these are the ups and downs of it," I would be diagnosing you, which is against the law, and I would be severely censured, if not have my certificate of competency removed. Yet the physician has a conversation with you, which I am not privy to, I do not know if your consent is informed or not, and you ask me for the upside and downside of this; and if I am the person you see or my colleagues, we can be censured as well for giving you any description whatsoever of what is going to happen you tomorrow morning if you sign this piece of paper. These are not exotic, ephemeral hypotheses; these things happen all the time. Any enabling legislation that deals with consent must have "informed" in front of it, and the consent must be obtained by the person who is going to do the procedure.

**Mrs Sullivan:** I have spoken—

**The Chair:** Mr Wilson.

**Mr J. Wilson:** She can have 30 seconds of my time.

**The Chair:** Okay.

**Mrs Sullivan:** If I can take the 30 seconds; I think it is important. I have had a conversation with Ms Andrews and—

**Mr Malkowski:** On a point of order, Mr Chair: I think we have to remember the time and give the other caucuses an opportunity to ask questions as well.

**The Chair:** Yes, Mr Malkowski. Mr Wilson has just offered up some of his time to Mrs Sullivan.

**Mr Malkowski:** Okay, thank you.

**Mr Poirier:** There go the 30 seconds.

**Mr J. Wilson:** I just wanted to show that we are cooperative from time to time in the opposition and that Mrs Sullivan and I do have a good relationship when it comes to being Health critics.

On that note, thank you for your presentation. I am glad to see—take this as a compliment, please—that you have changed your presentation slightly from the brief we received last year. I think it is much improved. I meant to organize a meeting with you on this; I am sorry I did not, but Mrs Sullivan did, and it seems to have worked out quite well. Because I was taken aback by the support of the ONA, which seemed to be fairly good support for the legislation, because, first—the thing Mrs Sullivan was going to get into—exactly who should be getting the con-

sent here? It needs to be answered. Second, my view of the legislation, when it comes to nurses—and I hope I showed, during the RHPA committee hearings, that my respect for nurses and ONA and other nursing associations is quite high

**Ms Cole Slattery:** You did indeed.

**Mr J. Wilson:** Thank you. I think you are being shoved aside in this legislation. You are being asked to get the consent, and then an advocate comes in, and it is a pretty complicated procedure you go through. If you want to just comment on that, and then I have one final, short question.

**Ms Andrews:** If I can respond first of all with, I guess, an editorial comment, certainly our verbal submission is somewhat different than our written submission, which we put in, I think, last August, and that is easy to explain. RHPA was in the full throes of hearings, discussions, all of the other things that went along with it. Our focus was on RHPA and in fact it continues to be on RHPA. So what you are seeing here certainly is some modification, although it does not go away from what our written submission was last year. We have simply had more time to focus on it of late. The second part of your question I will turn over to Lesley.

**Ms Bell:** I think as nurses we have always been advocates for the patient. One of the problems we see with this legislation is in obtaining a consent when there may be a question of our differing with the treatment order. We are the ones that have to obtain the consent in many of the instances, and we may in fact have a difference of opinion. We are asked now, by patients, what our feelings are, what some of the ramifications are. We assume, in a lot of cases, that the physician has given all the pros and cons, but in talking with the patient we find out that that is not true. We feel strongly that the consent should be obtained by the person who is prescribing the treatment, as opposed to the nurse who is there to carry out the course of treatment.

**Mr J. Wilson:** Thank you; that is quite clear.

You talk about a bipartite committee, and that is a good idea. If this legislation does go through, have you given any thought, as I believe we will eventually have hundreds of advocates running around the province, to a self-regulating college for advocates and that sort of structure? Maybe it is the wrong group to ask.

**Ms Cole Slattery:** You have that right. I believe in that like the boss believes in no proliferation of unions.

**Mr J. Wilson:** But setting aside the problems, it does work in some professions.

**Ms Cole Slattery:** It does not work for nurses, and we already have the midwives coming down the pike and God knows who else, God love them.

**Mr J. Wilson:** But my concern is that if we set up a bipartite committee or something, we are setting up more bureaucracy and more cost. We need more nurses, not more added to bureaucracy costs.

**Ms Cole Slattery:** Absolutely. I will sign that one too.

**Mr J. Wilson:** So I am looking for some sort of self-financing or self-regulatory model.

**Ms Cole Slattery:** There you go now. You are a smart man. You got elected. You can find money.

**Mr J. Wilson:** I think nurses are finding out that is not true.

**Ms Cole Slattery:** Our experience with Bill 208, the occupational health and safety laws that have seen the light of day in the last few years—ain't nothing in this world that is perfect except some of the things ONA does, but over and above that, the occupational health and safety mechanism seems to be a way in which workers have an honest, open avenue to voice their concerns and the boss has the same to explain why or when. Our experience living with that enabling legislation—I did not think 208 went quite as far as it could go, but to give Greg Sorbara credit, it went as far as he could get it—is that it seems to be working out the way that mechanism was provided for. We would suggest that you do not need to reinvent the wheel; you just need to look and see how that came about.

**Ms Andrews:** The other part, as it relates to a specific regulatory college or some type of forum—that might be good if you were dealing specifically with all paid advocates. But as I understand the system that is being proposed, we are not only dealing with what I would classify as professional advocates, but also with non-professionals who are not receiving any remuneration for the functions they are performing. I do not know how you would go about regulating somebody who is doing it on a voluntary basis in any event.

**Mr J. Wilson:** That is a good point.

**Ms Akande:** Thank you very much for your presentation. I recognize your expertise and certainly also your vulnerability in this situation. Is what you are really asking for greater specificity in the way the consent is obtained, who obtains it and how it is obtained?

**Ms Cole Slattery:** Yes. As well, it should be in the enabling legislation. These things should not be part of the regulatory process, which can change by whim or by will depending on the party in power. I think it does not make any difference what party is in power; everybody is looking for good laws in this particular area since we are all potential consumers. Probably the people at ONA would qualify more under some of the areas than others, but the fact of the matter is that there should be a greater degree of specificity of what is to be done, how it is to be done and by whom, within the legislation.

**Ms Akande:** Within the legislation.

**Ms Cole Slattery:** Yes, ma'am.

**Ms Akande:** If I can refer to page 4 of your submission, there is an assumption that the public is able to recognize incompetent or unsafe care etc. You are questioning that, and yet we do have vulnerable people and people who are not exactly receiving appropriate care. I am not saying because of your intervention, but it does happen.

**Ms Cole Slattery:** A lot of times, even over and above this particular piece of legislation, you go into a hospital to have a procedure done and when you leave you think: "That wasn't as bad as I thought it would have been. I am heartened by my experience and glad that I live in

Ontario." You would be making a positive comment on your experience and there could have been a number of very competent things done to you without your even being aware that they were done by competent people.

1700

**Ms Akande:** I recognize that. Are you asking that we trust—

**Ms Cole Slattery:** No, no. The other corollary is that you have a very unhappy experience, and we are not going to tell you, "It was because your physician was incompetent," or, "One of our colleagues was incompetent, that was part of your problem." We will just agree with you that you had an unhappy experience and hope it never happens again.

The recipient of the care does not always know that it is competent or incompetent delivery by the physician, nurse, or whoever. I do not know how you could specify that. Help me out with this, Noelle.

**Ms Akande:** If we are going to move from competent to incompetent, could we move to desired or not desired care? Would you agree that patients would be able to understand, or may be able to understand, whether the particular care prescribed for them is something they want to be a part of as a patient, or something they do not wish to have done to them or with them?

**Ms Bell:** If I can just answer, in some regard you have already indicated a problem, because as long as the patient is agreeing with the treatment there is very seldom a problem.

**Ms Akande:** That is right.

**Ms Bell:** It is when there is a question and they wish to refuse. I spent some time sitting on the Weisstub Inquiry into Mental Competency committee and after a long-drawn-out debate we came up with the fact that we could not determine criteria for competency. The question of competency is going to be raised in these areas and I think we have a real problem when we do not have criteria established to determine competency.

As a practising nurse, I can remember in a community hospital going by ambulance with a patient to the Ottawa Civic Hospital and having a physician come down, a resident in psychiatry, speaking to a patient for two minutes, determining the woman was competent and that she could sign whatever consent she wanted. I had to wait for an ambulance to come back to pick us up, and in the meantime she stripped and ran naked down Carling Avenue.

I think there is a question of fluctuating capacity, of competence, and you do not have anything in here, and I cannot see it coming out in regulation too quickly, on how to determine that. Without that, when do you get to the question of when a person wants to refuse to consent to treatment? I just think there are so many problems inherent in all of this at this time, and leaving it to regulation, as was said before, is not going to be the answer.

**Ms Akande:** I have one other question to ask, if I may, and that is about deferred consent. There have been those who have come before this committee on this and other days and asked for the right to assign someone to be responsible for making decisions around their—

**Ms Cole Slattery:** Not my ex-husband for me.

**Ms Bell:** The problem is, that is fine if you have—

**Ms Akande:** But you have choice.

**Ms Cole Slattery:** Not if I am laying there totally unconscious. You have to look in my wallet. Noelle is authorized to make—

**Ms Bell:** Or if that person is the one who routinely visits the patient. As care givers, you cannot expect us to stop everything and find out if in fact this is the person who has the preferential treatment to give consent on my behalf.

**Ms Akande:** But if that person is already assigned when the person was—

**Ms Bell:** Legally, is that going to continue to go for all aspects of care or treatment and everything? You get into the legal aspects of questioning whether this substitute decision-maker or substitute is in fact authorized to give consent to everything or not.

**Ms Cole Slattery:** Ask yourselves the question: Who in this room would you pick if you were not able to give consent? Who would you entrust both feet and your left ear and head to? Will you be safe? Yes, absolutely.

**Ms Akande:** There is another question: Would you better trust someone you have selected when you were well, or would you allow yourself to be up to the decisions of the unknown medical practitioner?

**Ms Andrews:** I think we are dealing with a couple of things here; first, the assumption that health care is delivered in some kind of controlled package. In fact, what we have is a mobile society. We have a breakdown of the family unit as we know it, and those are the people who, for the most part, would have taken care of these things for us.

Fine and good: I have a living will. I have determined I do not want treatment because of whatever diagnosis and now I travel to Windsor and I am in a car accident. First of

all, no one there knows I have a living will. The police cannot find my wallet or my purse. So now you have this whole cadre of care givers in the emergency department who cannot do anything else other than treat, and it totally removes all the good planning processes that I, as an individual and as a citizen, thought I could have in place to take care of myself.

I think what we are dealing with here is the notion that health care is fixed, and we do not have the breakdown of the family unit and we do not have an aging population who have none of their children maybe living close by and may not have any living relatives, for that matter. In terms of the consultation and expanding on the notions that are in these bills a lot of other things need to be considered.

**Ms Cole Slattery:** Take the converse: She has the living will, she is in Windsor, she is in an accident, she is not able to respond, she is unconscious, whatever. Do you want the nurses and doctors to stand there and wait until someone can be notified they can give consent to treatment? Do you want to be the person lying there waiting for treatment until someone can give the consent?

It is not that easy to call some of these shots, because in health care you only access it, for the most part, if not reluctantly, certainly by surprise. So you are more apt to be there thinking you were going to be having supper with Mabel, and guess what? You do not anticipate the delivery of about 70% of the care.

**The Chair:** Thank you, Ms Akande. Ms Helmstadter, Ms Cole Slattery, Ms Christianson, Ms Andrews and Ms Bell, on behalf of this committee I would like to thank you for taking the time out and giving us your presentation today.

A reminder that the subcommittee will be meeting briefly as soon as we adjourn. This meeting stands adjourned until 9:30 tomorrow morning.

The committee adjourned at 1707.

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First Intercession, 35th Parliament

## Assemblée législative de l'Ontario

Première intersession, 35<sup>e</sup> législature

# Official Report of Debates (Hansard)

Tuesday 10 March 1992



# Journal des débats (Hansard)

Le mardi 10 mars 1992

## Standing committee on administration of justice

Advocacy Act, 1991,  
and companion legislation

## Comité permanent de l'administration de la justice

Loi de 1991 sur l'intervention  
et les projets de loi  
qui l'accompagnent

Chair: Mike Cooper  
Clerk: Lisa Freedman

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# LEGISLATIVE ASSEMBLY OF ONTARIO

## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

Tuesday 10 March 1992

The committee met at 0945 in committee room 1.

### ADVOCACY ACT, 1991, AND COMPANION LEGISLATION

#### LOI DE 1991 SUR L'INTERVENTION ET LES PROJETS DE LOI QUI L'ACCOMPAGNENT

Resuming consideration of Bill 7, An Act to amend the Powers of Attorney Act; Bill 8, An Act respecting Natural Death; Bill 74, An Act respecting the Provision of Advocacy Services to Vulnerable Persons / Projet de loi 74, Loi concernant la prestation de services d'intervenants en faveur des personnes vulnérables; Bill 108, An Act to provide for the making of Decisions on behalf of Adults concerning the Management of their Property and concerning their Personal Care / Projet de loi 108, Loi prévoyant la prise de décisions au nom d'adultes en ce qui concerne la gestion de leurs biens et le soin de leur personne; Bill 109, An Act respecting Consent to Treatment / Projet de loi 109, Loi concernant le consentement au traitement; and Bill 110, An Act to amend certain Statutes of Ontario consequent upon the enactment of the Consent to Treatment Act, 1991 and the Substitute Decisions Act, 1991 / Projet de loi 110, Loi modifiant certaines lois de l'Ontario par suite de l'adoption de la Loi de 1991 sur le consentement au traitement et de la Loi de 1991 sur la prise de décisions au nom d'autrui.

#### REGISTERED NURSES' ASSOCIATION OF ONTARIO

**The Chair:** I call this meeting of the standing committee on administration of justice to order. I would like to welcome our first presenters, from the Registered Nurses' Association of Ontario. As you know, you will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Ms David:** It is a pleasure to be here today to make a presentation to the standing committee. I am Sheila David, a registered nurse and president of the Registered Nurses' Association of Ontario. Emily Phillips is a registered nurse and president-elect of RNAO, and Lynda Parks is also a registered nurse and executive director of RNAO.

The Registered Nurses' Association of Ontario is the professional voice for nurses in Ontario. The association protects the profession's interests and integrity while it influences and reflects changes in the profession and in the health care system as a whole. In keeping with our strategic directions, RNAO speaks out for nursing and health care.

RNAO promotes professional recognition of registered nurses and lobbies government and other organizations on issues that affect the wellbeing of nursing and client care.

Membership is voluntary. Our members currently number 15,000 and represent every segment of registered nurses in Ontario, from student to retired, including staff nurses in the community and in institutions, and nurses in research, education and administration.

RNAO wishes to draw the committee's attention to briefs previously submitted by two of our affiliated groups, the Gerontological Nurses Association (Ontario) and the Community Health Nurses' Interest Group. Our comments here today will substantiate and build upon many of the points made by these two registered nurses' groups in their submissions to this committee.

The RNAO commends the ministries of Citizenship, the Attorney General and Health for the pursuit of the government's equity agenda. We recognize the intent of Bills 74, 108 and 109 was to protect the rights of Ontario's most vulnerable citizens, the disabled and the frail elderly. RNAO believes, however, that this legislation is proceeding too hastily, and we have very serious concerns with regard to the practicalities of enabling this proposed legislation. It is RNAO's contention that the legislative package will unacceptably encumber the role of the registered nurse and thus compromise the quality of care provided to clients and substantially increase health care costs. We will outline our concerns in three specific areas.

The unique role of the registered nurse is not particularly well understood by either politicians or bureaucrats, except for those who personally have been on the receiving end of nursing care, for clients themselves understand that the registered nurse in fact integrates and coordinates the health care system. Registered nurses are the health care professionals who facilitate access to the whole spectrum of health care services. This function is entrusted to the registered nurse because the registered nurse is the only health care professional whose focus is the whole client, with all his or her biological, physiological, psychosocial and spiritual needs. The registered nurse has the broad educational background and sophisticated set of skills to perform this function capably.

RNAO acknowledges that many aspects of the registered nurses' role will change as a result of the reform agenda of the Minister of Health. Many more of our members, for example, will practise outside the institutional sector. We are confident, however, that the role of the registered nurse will not only be preserved but become, with even greater frequency, the access point to the health care system because of our ability to offer high quality and affordability.

To begin, we would like to comment on the definition of the word "treatment" as found in section 1 of Bill 109. Under this definition, all nursing interventions, every single nursing action, constitutes treatment and pursuant to section 5 must be consented to singularly. In practice, this

definition would prove to be too broad, especially with reference to sections 4 through 21.

Consider the following example: A seemingly lucid but frail 85-year-old man presents himself in the emergency department complaining of spells of dizziness and weakness. He is accompanied by his neighbour. He consents to the nurse's offer of assistance to help him undress while his neighbour leaves to make some telephone calls. The emergency department is very busy and the client is obviously distressed by the activity and noise level surrounding him. When the nurse subsequently approaches him to take his blood pressure, a routine assessment measure for ruling out a diagnosis of stroke, he seems confused and refuses this treatment.

With regard to this client's capacity, is he, as outlined in section 6, incapable with regard to this particular treatment, or is the strangeness of his surroundings affecting his capability, or has he just changed his mind about seeking treatment? If the nurse does judge this client to be incapable, there is no practical or expedient way for her to determine whether or not a guardian has been appointed or whether or not there is a valid power of attorney.

Section 10 of Bill 109 requires that an advocate visit this client promptly, but there is no way of guaranteeing that this will happen. In any case, the registered nurse is now unable to provide to this client even the most basic care and comfort measures, some mouthwash or a cold cloth for his head or even a cup of tea. There is no doubt that this client's civil rights have been protected, but what about his denial of access to immediate health care and comfort to which he also has a right?

We therefore recommend (1) that the word "treatment" be redefined to distinguish invasive and high-risk procedures from basic assessment and care measures; (2) that consideration be given to a blanket consent for a plan of continuing care; (3) that Bill 109 be amended to ensure that basic care measures are not delayed until an advocate sees the client, a substitute decider agrees to consent or the public guardian and trustee agrees to act. The client's interests might be further protected by requiring a second health care professional's opinion as to the client's mental capability before basic assessment, care and treatment is commenced.

The second point we wish to make pertains to the definition of "valid consent." RNAO believes that the principles, and more important the elements of valid consent must be clearly identified in order to properly safeguard the client's civil rights as well as the care giver's liability. If this same elderly client should require a radiological procedure, a chest X-ray or an angiogram, emphasis needs to be placed on not only who gives consent but who obtains the consent. We believe that obtaining the consent by the practitioner accountable for carrying out that treatment is a crucial element in valid consent.

RNAO therefore recommends (1) that the principle of valid consent be expanded to include the obtaining of consent by the health care practitioner accountable for carrying out the treatment for which consent is being given; (2) that actual indicators of a valid consent be identified.

The third point we wish to make centres on the issue of emergency treatment as laid out in sections 22 and 23 of Bill 109. The criteria identified for emergency treatment in the bill are totally unworkable in the real world of nursing and health care.

To refer once again to the example of our frail, elderly client who the registered nurse now believes to be incapable of consenting to treatment, who can possibly predict the outcome of non-treatment? What if the resultant harm that may befall our client is predicted to occur within 24 hours instead of the specified 12? If the registered nurse decides to commence treatment, she must ensure that the search for an authorized person to give consent on the client's behalf goes on whether the client is transferred to another unit, another facility or discharged home. Such a requirement will seriously encumber the role of the registered nurse, at great cost to the health care system.

Once treatment is started, is the entire plan of care implemented or only the intervention that is predicted to have the greatest likelihood of circumventing immediate catastrophe for the client? Should the nurse administer only the prescribed anti-clotting medication, or blood thinner, to prevent our client's pending stroke and then cease to monitor all vital signs? What would be the registered nurse's liability in this case?

Our recommendations therefore are (1) that the sections of Bill 109 on emergency treatment be amended to facilitate emergency intervention by care givers; (2) that the 12-hour time frame referred to in section 22 be deleted; (3) that the 72-hour restriction on the provision of emergency care found in subsection 22(5) be amended to ensure the continuation of client care as dictated by client need.

In summary, RNAO contends that Bills 74, 108 and 109 present major obstacles to the provision of safe and effective client care. We believe that widespread amendments are needed to achieve the kind of win-win-win situation we believe is possible; that is, the balancing of the client's civil rights and right to health care, the realization of the government's equity agenda and the protection of registered nurses' and other care providers' liability. This legislation must be simplified and rendered more user-friendly.

We understand through collaboration with our health care partners that government amendments to this legislation will occur. We urge you to share these amendments with us as soon as they are available so as to optimize the effectiveness of this consultative process.

**Mr Poirier:** Back on page 7 you talk about a blanket consent for a plan of continuing care. Could you take a couple of seconds to further elaborate on that? How would you see that in the practical sense—nurses are very practical persons—especially in the emergency ward? How would that work? What do you mean by that?

**Ms Phillips:** The way we would interpret blanket consent maybe is more in the long-term setting than in the emergency department, because the word "emergency" says it is a life-threatening, short-term problem. It is more the continuing care.

Someone is admitted into a nursing home. On admission to the nursing home, he may need only this type of care and treatment, but because of his dwindling health and his advancing age, while he is a resident in that facility his care may change. Therefore, we are looking at blanket consent on admission into the facility, when probably a family member or whoever has his guardianship is available. Today, families are so spread out that it might not be possible to obtain that when the patient's condition deteriorates.

**Mr Poirier:** Even though you mentioned that politicians or bureaucrats do not understand the role of nurses very well, I wish you would give us a bit more credit than that. But I agree with you that maybe in society, generally speaking, the role of nurses is not well understood. I tend to agree with that.

When we try to put ourselves in your shoes, if this goes forward as is, you would become incredible bureaucrats, especially in an emergency ward situation where a catastrophe comes in. Say a senior citizens' home has caught fire and they are all coming in at the same time. I do not know how the heck you could do this and not jeopardize the health of the people coming in all together at the same time, 30, 40, 50 or 60 seniors.

**Ms Phillips:** I agree that this is a nurse's worst nightmare. The next thing is a school bus accident, when we are lucky if the child remembers how to say his own name, let alone who has guardianship or who can sign for consent. They do not even carry identification on their persons. It would make it terribly difficult for us to do even that basic assessment.

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**Mr Poirier:** It is interesting that on your last page you changed your text; you made an oral difference. "We understand through collaboration with our health care partners that amendments to this legislative package"—you had written out—"are now under way," but you mentioned "will occur." I presume your scouts have mentioned to you that the parliamentary assistant keeps repeating that we will start working on the amendments after all the presentations have been brought forward.

**Ms David:** It is amazing what 24 hours can do.

**Mr Poirier:** It is amazing, yes. The paper is still warm from the photocopier.

The other point is that on page 7 you say, "The client's interests might be further protected by requiring a second health care professional's opinion as to the client's mental capability." I assume you say something like that faced by the fact that they would come forward and leave it as is. If you are going to have to go and get a second person when I am sure there is not one ward somewhere that is suffering or enjoying an excess number of nurses—correct me if I am wrong—for you to go and get a second person for an opinion is just Utopia. That would not stick to reality, would it?

**Ms David:** I think what we are trying to do is to indicate that there needs to be some solution to the difficulty people will find themselves in. You are quite correct in that finding another nurse who is available to make an assess-

ment would be difficult even today, but at least there is some sense that we need to have some opportunity to make sure the client's rights are recognized and also that the health care provider is protected.

**Mr Poirier:** If in your 10 pages the government members do not understand the downfalls of these bills between the great theory of it all that we all support, the great principle of equity that we all support, and if they want to know how it is not going to work, they just have to pass this and go to work next to the nurses and find out what kind of bloody nightmare that would be, right?

**Ms David:** Just to go back to your comment about politicians and bureaucrats for a second, that was not meant as an affront, but clearly those of us working in the profession are closer to the situation and have a greater understanding because we are into that particular situation. Part of the difficulty in drafting legislation, of course, is that unless you are part of the care giver team, it is very difficult to draft legislation that recognizes all the needs of all the providers as well as the clients.

**Mr J. Wilson:** Thank you very much for your presentation. You begin by asking the government and the committee to slow down on the legislation. Do you get the feeling there is some mistrust of health care professionals? What would be the impetus, for instance, in your health care settings for the emergency section that we have in the bill? Is there abuse going on? We have had witness after witness tell us that this is unworkable.

**Ms David:** I think there are two pieces to that and I will just comment on the first. There is no question that this legislation needs to be completed. What we are asking for, in terms of the slowing down of the legislation, is that there be some consistency and also that there be some consideration to what the outcomes would be if the legislation were to go through the way it is today. I do not think there is any difficulty in any of the health care provider groups that we do need this kind of legislation, but we do not need it the way it is written now.

**Ms Parks:** With regard to your question and the concern about language having been included with parameters for emergency treatment, I think that in any system, whether it is health care, education or transportation, a small number of incidents occur that gain a tremendous amount of publicity.

Our concern with having the restrictions that are put in this legislation is that things have been thrown slightly out of balance. Rather than serving the vast majority of what happens in health care—the vast majority of consumer issues as well as provider issues—the balance has come out of whack. A very small number of incidents, which perhaps could be provided for with some language, have toppled the balance and have outweighed perhaps 98% or 99% of what really happens in health care. The legislation as we read it and as we understand it and have examined it does not serve the people of Ontario, because it is out of balance.

**Mr J. Wilson:** I appreciate your comments very much. To correct that balance, in the recommendation where you suggest that the emergency provisions be

amended, did you have anything specific in mind of a model we could use there?

**Ms Parks:** We would certainly like to look at any wording regarding amendments on that section. None of the three of us is a lawyer; none of us has an LLB. We serve the professional interests of the organization. I am not a legislation drafter. I would need to see what legal counsel for a variety of constituents would put together and then we would have to look at that. I do not have that particular skill.

**Mr J. Wilson:** Sure; fair answer. You only mentioned briefly in the scenario, at the beginning, the role of advocates. You also mentioned the minister's future goals in health care and going towards a community-based setting, which may turn out to be a pipe dream. I think you know my views on that—you may know more about what the Minister of Health is up to than I do—about whether we will ever have the money. But in a community-based setting, you have to have advocates working alongside in the way the legislation is written now. You have alluded to some real problems there. Can you expand on that?

**Ms David:** The issue of consent in the community is more far-reaching than it is in the institution. If each client who comes on a service in the community has to sign a consent to treatment, regardless of what that treatment might be, that will encumber the nurse unnecessarily.

The role of the nurse in the community is very different from that of the institutional nurse. We may have some nurses, for example, who go into clients' homes and the type of treatment they would give the client may only be a blood pressure taking, but they are there to make sure the client is receiving the appropriate medications. They count out the medications for that person. They check the client's home. In the case of a 92-year-old woman who is living alone, it is important to make sure her surroundings are viable for her. To get a consent to have blood pressure taken, when that is a very basic assessment for a nurse, would unduly encumber the nurse.

**Mr Wessenger:** I would first like to ask you about your recommendation with respect to a blanket consent for a plan of continuing care. I would hope that the legislation presently provides for consent for a plan of continuing care, because certainly that is the intention. By "blanket" do you mean it would cover out-of-the-ordinary treatment?

**Ms Parks:** One thing that we struggled with, with all due respect, Mr Wessenger, was the intent. When we met with legal counsel from the ministry before we came here, when we were doing our preparatory work, and we had several questions for clarification in assisting us in preparing this brief, we asked: "What about this? What about this?" "Oh, well, that's the intent. The intent isn't that." Well, the words are the words that are on the paper. There are 117,000 registered nurses in Ontario, and my bet is that there are 117,000 different interpretations to the intent of what words may mean. If the intent is thus and so, it should be clearly stated, rather than anyone having to interpret, because we are going to have different interpretations of what the words actually mean. If the intent is to provide

for a way to have a blanket consent for continuing care, then that should be made clearer in the legislation.

**Mr Wessenger:** Do you have any problem, though, because the way the legislation now reads, you would still have to have an informed consent. I assume you would still have no objection to that.

**Ms Parks:** Certainly. Our president, Sheila David, mentioned at the outset that the Registered Nurses' Association of Ontario and our other partners in health care believe sincerely that informed consent is the cornerstone of providing health care to people in Ontario. It is not gaining the informed consent that is the problem; it is some of these other restrictions surrounding the definition of "treatment," parameters on hours, and the avoidance of clearly helping us with things such as blanket consent for continuing care.

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**Mr Wessenger:** I have another question with respect to the obtaining of consent. You recommend that the health practitioner who prescribes the treatment should, in all cases, obtain the consent.

**Ms Parks:** Yes.

**Mr Wessenger:** You do not think even minor cases of much less intrusive acts should be permitted to be delegated to an employee of the health practitioner, because the health practitioner is still responsible, still accountable under the legislation?

**Ms David:** No, we do not believe it should be delegated. We believe absolutely that the person who is performing the treatment should obtain the consent. We have believed that for several years. It was our understanding, when this legislation was first coming forward, that this would be in the legislation. When we spoke to legal counsel, we were informed that the intent was there, but we could not find it and neither could they. That is very critical to us. There are a number of things that could happen after a consent is obtained by other than the health care provider.

**Mr Wessenger:** You are saying, then, that you do not think the wording in section 4 is adequate.

**Ms David:** No.

**Mr Wessenger:** What would you recommend we put in there, not specifically, not in exact legal language?

**Ms Parks:** In looking at some of the things regarding consent, a very good book has been written by Gilbert Sharpe, who is legal counsel at the Ministry of Health and has been with the Ministry of Health for some time. I would advise all members of the committee, if you have not had an opportunity to review his sections on consent in that text, you will read in his chapters on consent his belief that the person who administers the treatment or the procedure is the one to gain the consent.

**The Chair:** Ms Parks, Ms David, Ms Phillips, on behalf of this committee, I would like to thank you for taking the time out this morning and coming and giving us your presentation.

**Ms Parks:** Thank you; our pleasure.

JOHN M. CLEGHORN

**The Chair:** I would like to call forward our next presenter, Dr John Cleghorn. Good morning. Just a reminder that you will be given a half-hour for your presentation. The committee would appreciate it if you would limit your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, please identify yourself for the record and then proceed.

**Dr Cleghorn:** My name is John Cleghorn. I am the head of schizophrenia research at the University of Toronto. I am based at the Clarke Institute of Psychiatry.

I was chairman of the department of psychiatry at McMaster University from 1975 to 1983. During that time, I was coordinator of mental health services for Hamilton-Wentworth and contributed to developing the most efficient system in the province with the lowest number of beds for population.

I was psychiatrist with the psychotic disorders team at McMaster University Medical Centre until mid-1991 when I left to join the Clarke Institute. I chair the professional advisory board of the Ontario Friends of Schizophrenics. I have been practising in the care of patients with schizophrenia for 32 years. I have been conducting scientific research on schizophrenia for 24 years. My work is presented and scrutinized by scientists from this and other countries at international meetings each year.

The views I present are based on scientific evidence that is tested in several countries and accepted by international scientific standards. I mention this because this kind of evidence is to be contrasted with fictionalized accounts of schizophrenia, such as appear in the movies, or by politicized views, such as those held by groups of people who are persuaded by a particular ideology.

Schizophrenia is a serious illness. Its victims occupy 4.1 million hospital days per year in Ontario. That is out of 51 million for the total. It is about 8%, more than stroke, which is 3.6 million. Schizophrenia affects 1% of our young people. It strikes in the form of a psychosis with delusions and hallucinations at approximately age 20, and it stays with its victims, most of them, for life. As such, it must be distinguished from problems of living. The problems of living such as unhappiness, and even marked distress caused by unemployment, are a clearly different category of phenomena. Yet there is gross confusion about that in the minds of the authors of the Advocacy Act and the other acts we are discussing here. In their minds, all problems of living and all psychiatric illnesses belong in the same category and they are all caused by social inequities.

There has been great confusion about this, and there is a need for public education on the distinction between problems of living and psychiatric illness. To this end, I and my colleagues have prepared a book of which we have donated many copies to members of the Ministry of Health and other ministries, and I present a copy for members of the committee. It is written for consumers to help them understand what psychiatric illness is about, what to expect out of treatment, and what is the difference between a problem with living and a psychiatric illness.

To say that schizophrenia is a problem of living that is perpetrated by the social environment is simply incorrect. There is the implication that professionals and family members might actually aggravate the problem of living that people are calling schizophrenia. This is absolutely, totally, factually incorrect. Schizophrenia is an illness. Schizophrenia is an abnormality of the development of the human brain. In some cases, that abnormality starts before birth. In other cases, it begins during brain development in adolescence.

What does this abnormality in brain development cause? Well, it causes abnormalities in the ability to handle complicated information. It causes oddities of spoken language. It causes difficulty in the emotional expression of ordinary human conversation, difficulties in understanding and interpreting the emotional meaning of what people say. The little kid ordinarily learns language and to communicate with other little kids and family members as though he did not even have to try. The little kid who is predisposed to schizophrenia is very awkward in these regions and other little kids tend to shy away from him, so he becomes an odd kid early in life. In some cases he may not even respond well to his mother, so that he does not bond, and she has the feeling there is something wrong from the very beginning.

There is a wide variety of different problems and they are not all the same in all cases, but all cases have one or other of them. As your child grows up and becomes a middle-aged child, shall we say, he becomes quite socially isolated. He tends not to have friends; he does not know how to handle that kind of communication. When adolescence comes along, life gets a lot more complicated, as you know. Social situations become more complicated; there are difficult rules to follow—all kinds of strong feelings. The kid predisposed to schizophrenia has real difficulty at this time and becomes increasingly withdrawn. He has to handle intense emotional stimulation and more complex cognitive information. What begins to happen then is a pervasive emotional withdrawal. The sense of vitality in that kid starts to be sapped away. It becomes flat and unresponsive. His parents have a horrible feeling that the kid they knew has left them. The body is there but the person is not the same.

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As that withdrawal process and shrinkage of emotional energy occurs, so it occurs that the awareness of that person—of himself or herself—in the environment becomes less intense. He may become unaware of whether he is actually initiating an action or a word, or whether someone else initiated it. He does not have a sense of willing; he loses his sense of will. At that point he may mutter something and hear it as though it came from over there. That is an auditory hallucination. He may look at something on the television and think, "Does that belong to me or is that just relevant to what the television man was talking about, or is that a special message directed to me?" He becomes confused between himself and the outside world. That is the beginning of a delusion. Schizophrenia, you see, is an illness that is an affront to the rights and freedoms of a person who has it.

What about treatment? We have taken our case through his or her development to the point where he now has a psychosis. That is what I was describing, the process of going crazy, of having a psychosis. Schizophrenia has two aspects: the deficits and the inabilities on the one hand, and the psychosis on the other. What happens next: treatment. The first step in treatment is to give anti-psychotic drugs. Anti-psychotic drugs reduce the hallucinations and delusions. They improve the problem-solving thinking. They improve the ability to communicate with others back to the level the person had before and generally restore their rights and freedoms. This is in contrast to what some people say, that the anti-psychotic drugs are mind altering and dangerous. That is factually incorrect. I could say that a drug like LSD, cocaine or street drugs are mind altering and dangerous. They cause psychosis.

The drugs have side-effects, like any drug. They can cause mild tremors or other mild motor disturbances. In some cases they can cause some irreversible effects such as spontaneous movements of the lips, fingers or toes in 3% of people; cumulatively, up to 30%. Fortunately those effects are less serious than the illness itself. Fortunately research is bringing along to us new medications that are relatively free of side-effects.

The next stage in treatment is rehabilitation and here the attitude changes completely. Here the Advocacy Act and the attitudes of the professionals in rehab programs are exactly in line one with the other, because the aim is to provide the patient, who has now recovered from his psychosis, with greater autonomy. The difference in approach, however, is that one is legal and the other involves teaching and assessing the person's skills and deficits and helping to teach him overcome some of those deficits which I mentioned earlier on.

In so doing, the rehabilitation workers, the family and the client—we call them clients now, not patients; it is not medically dominated anymore—these people are in a partnership to attempt to achieve independent living for this person. The question is, do the consumers of this kind of service, which is being developed in this province by the Ministry of Health for many years in a very enlightened way, do the 10,000 consumers, that is schizophrenic patients in this province, really want more advocacy? What do they need?

#### Interruption

**The Chair:** Excuse me, Dr Cleghorn. Just a reminder that this is an extension of the House and there will be no comments or noise coming from the people seated here viewing.

**Dr Cleghorn:** We need a survey. We need a sample of the 10,000, not just the voice of one or two dissatisfied people. If they are dissatisfied people, it may be that they have been mistreated. It may be that their caretaker should be charged with malpractice. That would be the approach I would recommend rather than listening excessively to the voice of one or two disenfranchised people.

One thing that is quite clear is that the power of doctors to admit patients involuntarily is an offensive thing these days and I think it is time to put an end to that. There are

other ways of doing it in other jurisdictions, and after all this is a power of the state given to doctors. It seems to me there is little point in setting up a way of protection, of protecting citizens against doctors, when the power they have been given belongs to the state in the first place.

In order to emphasize the point, I have brought along a form 1. That is for involuntary admission and I would like to put it on the table here by way of saying I do not want to sign them any more. Why do we not work out a different mechanism?

In conclusion, the specific recommendations for amendments would be found in the contribution of the Ontario Friends of Schizophrenics, but I just want to say that if the new acts are unmodified, the following criticisms must be expected to be heard over the next 10 years. Why 10 years? Because that is about the average life of the Mental Health Act. They change about every 10 years.

First of all, schizophrenia erodes the rights and freedoms of people who have it. Treatment restores those rights and freedoms. Withholding anti-psychotic medication minimizes the chance of recovery. I did not make this point before: The longer the symptoms are in place the more difficult it is for them to be removed, so anything that interferes or prolongs the time between the onset of the symptoms and the instigation of treatment will make the patient worse. Thus, the Advocacy Act, which could delay treatment, may do exactly the opposite of what it is intended to do in leaving a person afflicted with a disorder that interferes with his rights and freedoms.

Persons who promulgate the view that schizophrenia is a social problem discourage proper treatment and therefore do damage to the health of people with schizophrenia.

It will cost many millions to implement these laws. This province spends less than \$1 million a year on research into this terrible disorder. You can see where I suggest some extra funds be allocated.

**Mr Poirier:** Dr Cleghorn, I have no parti pris. I am trying to look at this as objectively as I can. In the first two weeks of our committee hearings we have had some people come forward, psychiatric survivors and other groups and individuals, and hold a very strong if not violent opinion as to how they are treated, considered or whatever, including at the Clarke Institute of Psychiatry. As I said, I am not coming from a partisan position or whatever pertaining to that, but would you remind us which groups you feel support the principle but may object to the practical application of this law? Have you had discussions with groups on the outside of the Clarke Institute, either friends of patients, patients—

**Dr Cleghorn:** Oh, yes.

**Mr Poirier:** —former patients, or whatever? Could you elaborate a bit on that, please?

**Dr Cleghorn:** They think it will interfere with the treatment they need.

**Mr Poirier:** I see. We had a young schizophrenic come in from Guelph and he recommended that he should be able to write his consent on a permanent form and in a certain sense that whenever he is found to be shying away, if nothing else, from his treatment, friends of his, the person

who is his responsible person, can bring him in and force the pre-prescribed treatment on him to make sure, because they know this treatment will help him get through. Are you comfortable with that proposal, a long-term permanent consent that says, "This person is my guardian here"?

**Dr Cleghorn:** A consent in advance while able to consent, yes.

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**Mr Poirier:** That is right, and if that person brings me in, this is the treatment you will give me because this is what I consent to and you will do it to me even though I may appear to be opposing it right now. How do you feel about that?

**Dr Cleghorn:** Yes, that would be the best thing. You see, we know these people over long periods of time. We are friendly with them, you see, so they do not object to it so much. They do not feel they are being mistreated. You have to cajole them, encourage them and say, "Hey, you remember signing that, don't you?" and the person will usually say yes and come around. Usually we do not have to go to these extremes, but to have that as a backup would be very helpful.

**Mr Poirier:** Why would these groups that came forward in the first two weeks hold such a violent opinion as to how—

**Dr Cleghorn:** I really do not know, because they do not come to us, you see. One would like to understand that better. Every profession has its people who have their shortcomings. Maybe some people have been very badly treated. Maybe they should be laying charges.

**Mr Poirier:** You do not have any contacts with them? They do not dialogue, because it is very upsetting to find such a black-and-white opposite view, 180 degrees, in the perception of treatment, required treatment, methodology of treatment. As I said, some people come here violently opposed to what has been done to them—

**Dr Cleghorn:** Yes.

**Mr Poirier:** —by your profession at the Clarke Institute of Psychiatry and elsewhere. That is why I want to hear, from you, the other side of the coin, to try to get a more balanced view, because if you had been here you would have been extremely upset, also, with what people had to say. It is very confusing for us trying to determine how you look at rights.

People come forward and say, "I have a consent that says, 'Give me this treatment whether I appear to want it or not.'" Others come in and say, "I've been tortured, my mental and physical health have been permanently damaged by what has been done to me there."

**Dr Cleghorn:** Unfortunately some of those people are suffering from an illness that involves delusions around their care, so it is not really a true representation, but it is a very difficult judgement to make as to whether that is the case.

**Mr Sterling:** I was absolutely amazed; I had not heard the figure that 8% of our hospital bed days in Ontario were occupied by schizophrenic patients. I was at a medical-legal conference last May on a panel dealing with living

wills and advance directives etc, and one of the physicians on another panel whom I listened to indicated that there was only \$1.5 million a year spent on research into schizophrenia in Canada. Is that correct?

**Dr Cleghorn:** No. It is slightly less than \$1 million spent in Ontario. I do not have the figures. There really is a need for a great deal more and certainly appeals are being made to the Medical Research Council of Canada for a greater involvement.

**Mr Sterling:** So 8% of our hospital days are being utilized by schizophrenic patients and we are going to spend \$20 million to \$30 million for an advocacy system. To me that does not—

**Mrs Sullivan:** Or more, substantially more.

**Mr Sterling:** Or more. It amazes me how far out of whack we can get in government in terms of the priority of spending and dealing with different kinds of problems.

I am really happy you came today because often in parliamentary committees we give undue credibility to people who really do not have any formal qualifications or proof of qualification, and I am glad you are here. With regard to treatment of schizophrenic patients, is the treatment offered in Ontario and in Canada much different than it is in the other advanced nations of the world?

**Dr Cleghorn:** I think it is better here than in most places because of the health care system and accessibility. There has been a very enlightened attitude in our Ministry of Health for many years in terms of interacting with professionals and with clients and families in determining what their needs are. It has really been wonderful. I am not saying it is as accessible as it should be to every person with this disorder in the province, but overall it is pretty good. Now, as to the people who are so unhappy, I do not know. I mean, they do not come and explain their views to us.

**Mr Sterling:** Within our hospitals that are dealing with mental illness, there is an advocacy system in place.

**Dr Cleghorn:** Yes.

**Mr Sterling:** How is that working?

**Dr Cleghorn:** My colleagues feel it is justified in the mental hospitals system. They do not feel it is necessary in the general hospitals system or in the rehabilitation clinics such as I have described.

**Mr Sterling:** The other point you brought forward in your presentation was your dislike of the role of the doctor taking on the power of, in effect, incarceration.

**Dr Cleghorn:** Yes.

**Mr Sterling:** You would like the state to take that back.

**Dr Cleghorn:** Yes.

**Mr Sterling:** Perhaps in writing you could explain to me or to other members of the committee who are interested in it what the other options are. Can you summarize what the options might be?

**Dr Cleghorn:** I know the legal people here who have been working on these acts are very familiar with them and they are very aware there are different methods. I have

discussed this personally with Gilbert Sharpe who says he prefers to have doctors do it because it is the cheapest way. We are being pilloried for having excessive powers now, and I think enough is enough. We have to find another way, even if it is not so cheap. There are other methods. There is a method in Great Britain that is not expensive.

**Mr Sterling:** Which is?

**The Chair:** Thank you, Mr Sterling.

**Mr Sterling:** I was interested in—

**The Chair:** We have five members in four minutes. Mr Malkowski.

**Mr Malkowski:** Certainly the information you have provided is very clear in distinguishing disorders such as schizophrenia from problems of dealing with daily life. I have a question for you: Does the Clarke Institute have a formal system in place to deal with patients' complaints?

**Dr Cleghorn:** Yes.

**Mr Malkowski:** Could you briefly elaborate on that system, how the process works and how you deal with patients who have concerns or complaints?

**Dr Cleghorn:** There are two levels. First of all, the staff and the patients have a very open communication system so that small problems can be brought forth and remedied very easily. There are complaint boxes around if people want to write complaints. But more particularly there is the system of appealing and refusing: Those who wish to refuse treatment or who wish to be discharged are free to call review boards. There is the whole legal apparatus that is operating every day.

**Mr Malkowski:** Following up on that, Dr Lorne Martin spoke yesterday, as a family physician as well as having done psychiatric interning, on the abuse of clients' rights and some concerns that he personally has seen occur. Do you agree that in some cases there are some areas of abuse within the psychiatric system, that there are times when mislabelling of schizophrenia and other disorders occurs?

**Dr Cleghorn:** Of course.

**Mr Winninger:** Dr Cleghorn, I too share Mr Poirier's concern, because we have heard the other side of the issue. We know that back in the 1950s psychiatrists or surgeons were performing lobotomies and lobectomies; no one worried about consent or advocates then. Then into the 1960s, a lot of electroshock treatments with unpleasant side effects; again no one worried about advocates or consent. Now we are into drug therapy. I have a schizophrenic in the family. Drugs stabilize him; there is no doubt about it. They remove a lot of his delusional behaviour. They have not cured him and I would suggest that it might be a little on the paternalistic side to say: "We can treat these people. We can make them better and we are concerned as medical health care practitioners about the kind of safeguards" that we as a government would like to put in place. Is there any middle ground there?

**Dr Cleghorn:** I am sorry. I did not understand the question.

1040

**Mr Winninger:** I guess the question is, do you not see a value in these kinds of procedural safeguards being in place so that some of the abuses that have been complained about in the past, and even in the present, can be reduced?

**Dr Cleghorn:** I think it would be one thing to have advocacy available on request just as various legal safeguards are available now. That would be one thing, and it is another thing to have it made mandatory and filtered through the entire mental health system.

**Mr Winninger:** I know time has almost run out, but you seem to be prepared to tear up the form 1, which provides some criteria for a psychiatric assessment. What would you replace it with? I still have not heard.

**Dr Cleghorn:** It is not my job to do that. This is a legal problem. I would say there are other very plausible methods in other jurisdictions that diminish the power of the doctor and share it with another professional, you see—

**Mr Winninger:** I see.

**Dr Cleghorn:** —so that the doctor becomes less of a lightning rod. The power to sign a form and to admit a person to hospital against his or her will is a power that is held by no other member of society and it is seen as anachronistic now and I agree with that.

**The Chair:** Dr Cleghorn, on behalf of this committee, I would like to thank you for taking the time out this morning and giving us your presentation.

#### ONTARIO FRIENDS OF SCHIZOPHRENICS

**The Chair:** Let's call forward our next presenters from the Ontario Friends of Schizophrenics. As you are aware, you will be given half an hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. Could you please identify yourselves for the record and then proceed.

**Mrs Etchen:** My name is Elsie Etchen and I am the president of the Ontario Friends of Schizophrenics. With me are June Beeby, the executive director of our organization, and Mr Wolfe Goodman of Goodman and Carr, who is our legal adviser for this morning.

Ontario Friends of Schizophrenics is an organization of approximately 3,000 family members who have direct knowledge of schizophrenia through their experience in caring for a family member who suffers from this disease. Many other people daily contact our provincial office and our chapters for information and help.

We are very grateful to the Ontario Trillium Foundation whose grant has made it possible for us to have Arthur Fish analyse the legal implications of the bills and help us understand them. This is the first time ever that we as an organization have been able to appear before a committee like this one, representing our members, and present you with a comprehensive brief.

On page 2 of our brief you will find a description of schizophrenia. As you have just heard from Dr John Cleghorn, in schizophrenia the brain does not develop normally.

Schizophrenia is the most prevalent of all serious psychiatric illnesses and is also one of the most expensive, as Dr Cleghorn has said. Everyone has a 1% chance of developing schizophrenia some time in his or her lifetime, and at this particular time in Ontario there are about 50,000 people, or perhaps a few more, with this disease.

As Dr Cleghorn has said, schizophrenia can be treated with anti-psychotic medications, but the common experience that we have in Ontario Friends of Schizophrenics is that many of our family members resist taking medication and avoid going to hospital because their judgement is distorted and they do not think they are sick.

During these hearings, a number of our family members have shared their experiences in trying to get care for a relative. Often their efforts have been frustrated because of restrictions in obtaining psychiatric care under the Mental Health Act. They have also told you that their family members are highly suggestible and some resist treatment and hospitalization after being told by an advocate of their right not to be treated or hospitalized.

These bills are based on principles that we as an organization endorse; that is, enhancement of autonomy, recognition of capacity, preservation of rights and providing for substitute decision-making. The Consent to Treatment Act parallels some of the provisions in the Mental Health Act, with which we are very familiar. While we endorse these principles, we find the bills do not provide the balance between protecting legal rights and providing speedy access to treatment. Rights are emphasized, protecting wellbeing is not.

Before turning to the bills themselves, may I say how frustrating we have found the consultation process to date. Ontario Friends of Schizophrenics has had dialogue with officials because we have been persistent and because we have done our homework in making some solid proposals for improvements in the legislation. We have been unable to meet with a single minister of the three ministries concerned, despite repeated requests and despite the fact that people with schizophrenia are one of the largest groups in the vulnerable population that will be affected by these bills.

We still have no idea of what kind of amendments there will be. We could have made ever so much more of a contribution—and this is true of many of the other concerned groups—if we had been asked to comment on the suggested amendments, if we had been asked to share in what should be, after all, a non-partisan exercise, rather than having to keep on insisting on being included in the consultation process.

We have presented a very detailed list of amendments we would like to see to the bills and I will just go over each bill individually with some highlights.

You have heard some very compelling stories from several of our family members. There is no question that these care givers, and many more like them, are real advocates for their relatives.

Last spring we wrote to Premier Bob Rae asking that families be recognized as advocates for their relatives with schizophrenia. He replied on May 15, 1991: "Your plea for more involvement in the mental health care decision-making

process is indeed needed. The full partnership of consumers, families, service providers and medical practitioners is a necessity." Bill 74 makes such a partnership impossible and it must be changed.

On pages 13 and 14 of our brief, we summarize the changes that must be made to Bill 74.

Among the most important of our recommendations are the mandatory participation of families in the Advocacy Commission and the appointments advisory committee, if this is retained. Mandatory advisory committees: One must be an advisory committee of families. The definition of "vulnerable person" must be changed so that the seriously mentally ill get first priority in the provision of individual advocacy services. The Advocacy Commission must be publicly accountable. Advocates must be trained and certified so they will be knowledgeable about the people whom they serve. Vulnerable people must be protected against untrained, unqualified and incompetent advocates. We urge you to look at some of the precedents in the Regulated Health Professions Act, which this government has just recently dealt with. There must be a definition of capacity to instruct an advocate. Non-instructed advocacy must be the exception to a general rule that advocates must act on capable, voluntary and informed instructions.

I also want to remind you that this bill gives more access to a private home for an advocate than is the present case for a police officer, and we are asking you to protect the privacy of the homes of families.

In relation to Bill 108, I will deal with part of this and we will ask Mr Goodman to deal with part of it too. I will speak to the first section, or the first group, and then I will ask Mr Goodman to speak to the second.

We agree that there needs to be a substitute decision-making process set out in legislation for persons suffering from schizophrenia. There are persons suffering from schizophrenia who agree to be treated and those who refuse treatment.

One important area where this committee can make a real difference in improving Bill 108 is regarding the powers of attorney for personal care. We ask you to enact a scheme for pre-validated powers of attorney. We have included proposed amendments in appendix 2 of our brief. Of all our proposed amendments to Bill 108, this one offers a very important opportunity to improve the situation for people with schizophrenia.

This proposal really does not break new ground. Similar provisions are now found in at least the states of New York and Massachusetts. It would allow people with schizophrenia to work out plans for their treatment when they are capable, knowing that those plans would be followed with no delay when they become incapable, and it would avoid the expense of guardianship as well as the difficulties.

1050

For those who refuse treatment, the guardianship provisions in sections 52 to 62, that is, court-appointed guardians of the person, create enormous barriers for us. We have been told repeatedly we do not understand the benefits of these sections and the related sections in Bills 109 and 110. I would like to just refer briefly to something

called the Fram report. This was the basis on which this legislation was built. I would like to read a brief paragraph about what this committee said about court-appointed guardians. It said:

"Furthermore, they believe the cost involved in the process is also unnecessary, as the state of incompetency is transitory, and there are no other decisions a guardian would be required to make. Committee representatives from the Ontario Hospital Association, the Ontario Medical Association and the Ministry of Health believe that the recommendations regarding patient refusal are more suited to chronic incompetency and long-term care situations."

So you are dealing with guardianship provisions that really do not suit us, and some of the people on the Fram committee endorsed this point of view. I would like to add parenthetically that we were not part of the group reviewing the substitute decision-making process.

We have been told that approximately one third of our members' relatives would refuse to sign a pre-validated power of attorney. That is a very considerable number of people. And perhaps up to one half of all the people who have schizophrenia at some time in their lives do refuse treatment during the course of the disease.

We want to understand what we do not understand and we have asked Mr Wolfe Goodman, our legal adviser, to discuss with you the import of sections 52 to 62 and related sections in other bills. Also, we have taken the personal story you heard from Margot Hamblen, who is here. We have assumed these bills were in force and we have described the problems they create. This has been distributed to you today: Will Guardianship Work with Persons Severely Ill With Schizophrenia?: A Case Study. Our answer is definitely no. We would like Mr Goodman to tell you now what we think the import of these sections is for us.

**Mr Goodman:** In dealing with the typical situation where the individual has not previously given anyone a power of attorney for personal care, but the person is now suffering a severe psychotic episode as a result of schizophrenia, some method has to be found to ensure prompt admission to a hospital or psychiatric facility where a person can be treated promptly, appropriately and discharged as soon as the psychotic attack is over.

You have heard from Dr Cleghorn that he and presumably other medical practitioners who are experienced in the field have a rather strong aversion to making use of the extremely drastic provisions of the Mental Health Act in order to admit a psychotic patient to a psychiatric facility.

What are the alternatives that are available? I suggest with respect that unreasonable obstacles are being placed in the way of a family member who seeks to have a schizophrenic relative admitted during a psychotic attack and to have that person treated. Under Bill 109, section 4, no health practitioner can administer treatment to a person unless either of two conditions exists: Either "he or she"—that is, the health practitioner—"is of the opinion that the person is capable with respect to the treatment, and the person has given consent"—and obviously that does not apply to someone who is suffering from a psychotic attack, who is not capable—or second, "he or she is of the opinion that the person is incapable with respect to the treatment,

and another person has given consent in accordance with this act."

In those circumstances, subsection 10(1) requires the health practitioner to advise the patient that the practitioner considers the patient incapable and to give the patient written notice that the patient can meet with an advocate and can make an application to the Consent and Capacity Review Board. The practitioner must then notify an advocate who must promptly meet with the patient, explain the effect of the finding of incapacity and the right to make an application to the board. Then the advocate can report to the health practitioner under section 10 that the patient has decided not to make an application to the board. Only if the health practitioner has received such a report from the advocate can the health practitioner provide a treatment which has been refused by the psychotic patient, but which has been requested by a caring family member.

Now, with all due respect, this is not the way to treat a human being who is suffering a psychotic attack as a result of schizophrenia. It elevates formal patient rights to such a degree that they are actually harming the people who are supposed to be helped.

In a proportion of cases, it is possible to obtain a power of attorney from a lucid patient during a period of remission, authorizing someone to act on his or her behalf and to consent to medical treatment on his or her behalf. Unfortunately, as Bill 108 and following have been drafted, this is not capable of achieving the desired care in the case of a psychotic patient. Let us look at that.

In the case of powers of attorney for personal care, subsection 47(9) of Bill 108 states, "The power of attorney is not effective until it is validated in accordance with section 49." Then there follows a cumbersome procedure involving an application to the public guardian and trustee. An assessment is then required of the mental capacity of the grantor of the power of attorney, and if the assessors certify that the grantor is incapable, then formal statements to this effect are filed with the public guardian and trustee.

The public guardian and trustee then appoints an advocate to meet with the grantor and explain his or her right to oppose the validation of the power of attorney. The advocate then reports to the public guardian and trustee about the meeting and whether the grantor opposes the application. Only then can the public guardian and trustee validate the power of attorney, and if the public guardian and trustee declines to validate it, an application can be made to court.

With respect, this might well be a suitable method when you are dealing with a disorder like Alzheimer's disease, but it is entirely inappropriate when you are dealing with a psychotic attack of a psychiatric patient. The person is in a state of extreme tension and requires immediate medical attention. He or she is refusing the medical attention typically because he or she does not believe that he or she is ill, which is a normal concomitant of the psychiatric situation. Even if that person has, while lucid, provided a power of attorney for personal care, Bill 108 goes out of its way to provide unnecessary delays in ensuring that care is available.

Bill 109 contains similar problems. Subsection 13(1) provides that instructions with respect to treatment contained in a power of attorney for personal care are valid even if the power of attorney has not been validated under the Substitute Decisions Act, Bill 108. However, where a family member tries to give consent under Bill 109, clause 17(b) requires him or her to make a statement that "indicates that he or she has no reason to believe that the incapable person might object to him or her making the decision to give or refuse consent."

1100

If we are dealing with a person who is suffering a psychiatric attack, a psychotic attack, as a result of schizophrenia, it is likely that person will be objecting very volubly at the time to receiving treatment. How can the family member make the statement referred to in clause 17(b) in good conscience, notwithstanding that there has been a power of attorney given when that person was fully competent, authorizing that treatment?

Section 19(2) of Bill 109 states, "If a person is sixteen years of age or more and objects to being admitted to a hospital or psychiatric facility, only a guardian of the person appointed under" sections 52 to 62 of Bill 108 can consent to his or her admission. That means that a power of attorney for personal care cannot be used to authorize the attorney to have the patient admitted to a hospital or psychiatric facility. This is wrong in principle in our submission.

In the more typical situation, where there is no power of attorney given, we have an extraordinarily cumbersome procedure that should take a sufficiently long period that the psychiatric patient is either over his or her psychotic attack or has fled from any possibility of being treated. It is not conducive to proper treatment. There must be a method by which a caring family member should be able to get a patient admitted to a psychiatric facility.

We recognize that there are important questions of personal integrity and civil rights that have to be respected. But unfortunately there is a very serious conflict between the danger a person can do to himself or herself by refusing treatment at a time when that treatment is needed, and the need to have that person admitted for treatment by a caring family member. The situation is even more extreme where you have a consent that has been given when the person is lucid. Surely it should be a matter of government policy to validate that arrangement and to do everything possible to ensure that a person who is given power of attorney for personal care while competent is able to have that implemented.

**Mrs Etchen:** We will just conclude by talking a bit about Bill 109. We have tried to prepare amendments to harmonize the bill so that there are common definitions throughout the bills. In addition we have proposed many other amendments. We have submitted them in our appendices.

We are particularly concerned about the definition of "capacity" and we ask you to consider the conflict between the provisions of these bills and the Mental Health Act itself, as amended by Bill 110.

We are particularly concerned about the admission of an involuntary patient who can be detained, restrained, observed and examined. But bills 108 and 109 allow a guardian with custodial powers to take a person with police assistance to a psychiatric hospital and admit him or her, and probably an advocate would have them out soon, because these provisions violate the Mental Health Act. This probably also applies to the temporary guardianship provisions of the public guardian and trustee. We see these conflicts in the bills and we ask you at least to review them and remove the internal contradictions.

As was discussed here yesterday, there are rumours all around that the government plans to withdraw these bills, or at least Bills 108, 109 and 110. These bills, with Bill 74, are a package and it is very difficult for us to see how you could possibly proceed with Bill 74 on its own. If you do proceed, however, please take all bills as a package and please make sure that the family care giver advocates, whom we represent, present the unique needs of the people with schizophrenia and that these needs are reflected in the legislation itself.

**Mrs Sullivan:** Before I start with my question, I want to congratulate the Ontario Friends of Schizophrenics for the work it has done in preparing this report. It has been extremely useful. As you know, we have met on several occasions in relation to these bills, and the work you have done not only in preparing this report but all the way through that consultation period has been useful and will contribute to well-drafted, important legislation.

You joined yesterday with the coalition of care givers and service agencies requesting that the bills be withdrawn as a package and brought forward in a redrafted form. Much of your redrafting clearly would go a long way to a positive end in that matter. Would you, for the record, like to speak particularly about your participation in that effort?

**Mrs Etchen:** How far back would you like me to go? In the process, we prepared something called Through the Maze. We distributed this widely. I think our executive director is beginning to get a little anxious that we are distributing things and not recovering our costs. We have distributed maybe 500 or 600 copies of that, with the coalition that we met yesterday.

Our position is the same as the coalition's, that the bills stand or fall as a package. The ad hoc group met over three or four months. We identified our common problems. We do not all have the same problems, but we all have a certain number in common, and we say that the bills would benefit greatly if they were withdrawn. We could sit down and talk to the legal draft people and, with them, understand the implications, and they could understand the reality we are facing.

**Mr Sterling:** I want to use my question not to laud you, because you know I already do, but I would like to ask Mr Winninger, on your behalf, is there a philosophical problem with utilizing a power of attorney for personal care for involuntary treatment in a mental institution or hospital?

**Mr Winninger:** We are certainly looking at the issue and the recommendation that there be pre-validated powers

of attorney. I would ask Mr Goodman whether he thinks perhaps pre-validated powers of attorney might be restricted where the donee of the power is a family member.

**The Chair:** This is Mr Sterling's time, I would like to remind you.

**Mr Sterling:** That's fine; I am quite willing.

**Mr Winninger:** It is kind of a dialogue whether perhaps it would be appropriate where the family member is the appointee but not perhaps where a friend or stranger is the donee.

**Mr Goodman:** The idea clearly is to find a caring person who is an appropriate donee, and families differ considerably. In some cases they are very close and in some they are not, and in some cases one can imagine that a close friend might be the appropriate person. I do not think there is any blanket answer. It is a question of fact.

We know this is a very serious responsibility. A power of attorney for financial matters is a serious concern. A power of attorney that authorizes someone else to act on your behalf for medical or psychiatric care is far more serious. One ought not to sign it lightly, but it is interesting that a significant number of schizophrenic patients are prepared to sign such powers of attorney during periods of lucidity.

**Mr Winninger:** We have heard very compelling presentations that would support your comment.

**Mr Malkowski:** Thank you for your very comprehensive presentation. Going through your recommendations, on page 14 you are talking about mandatory advisory committees. You are saying there should be an advisory committee including family members and health care professionals. I am just wondering about the consumer groups, people who have already had experience in this area, like psychiatric survivors or people who have been misdiagnosed. Do you think it is important to get the consumer perspective on the advisory committee? You would then have your family members, health care professionals and the consumers. Do you think this would provide a balanced perspective?

**Mrs Etchen:** What we are talking about are advisory committees to the Advocacy Commission itself. The bill makes provision for them to be appointed. We were thinking there would be one advisory committee of families and another advisory committee of professionals. Certainly we would have no objection whatsoever to an advisory committee of consumers. The bill as it is written, as you know, provides for a majority of the persons on the Advocacy Commission itself to be consumers, so perhaps there is not the same necessity for consumers to be a special advisory group. Families were not included at all in the bill as it is presently drafted. But certainly we have no problem at all with consumers having a special advisory committee.

**The Chair:** Mrs Etchen, Mrs Beeby and Mr Goodman, on behalf of this committee, I would like to thank you for taking the time out this morning and coming and giving us your presentation.

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CANADIAN MENTAL HEALTH ASSOCIATION,  
ONTARIO DIVISION

**The Chair:** I would like to call forward our next presenters from the Canadian Mental Health Association, Ontario division. Good morning. Just a reminder that you will be given a half-hour for your presentation; the committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Mr Tapping:** We are going to endeavour to keep it less than 15 minutes. We have a brief. We are not going to read it to you. I urge you to read it.

Good morning. My name is Hugh Tapping. Beside me is Carol Roup. Before I begin, I have asked the clerk of the committee for one of those standby-list places. After hearing the previous presentations this morning, there are many important things you should hear from me as a citizen who has been involved in mental health and advocacy since 1967, and not as a representative of any organization or agency. There are many things you heard this morning which are not true; they are not real and they are personally offensive. I am one of those people they were talking about. My philosophy says there is no such thing as "us" and "they." Like it or not, we are all in this boat together.

I am a member of the board of directors of the Ontario division of the CMHA. I am on the executive committee. As part of my responsibilities, I am co-chair of the policy advisory committee. Carol, beside me, is our staff person for that policy process.

The Ontario division of CMHA is a member of the Ontario Advocacy Coalition, and we support its brief to you. As Mr Malkowski said a month ago today in his statement to this committee, vulnerable people, those of us who experience difficulty in expressing our wishes or knowing our rights, are especially vulnerable to abuse, neglect and exploitation. I would like to correct Mr Malkowski's statement, however. It is not just difficulty in expressing our wishes or knowing our rights; there is that standing-up-for-our-rights issue with which we have difficulties, not always of our own making.

I would go a bit further and point out that the organization for which I am speaking today was founded over 70 years ago to try to address the abuse, the neglect and the exploitation endemic in our mental health system.

Father Sean O'Sullivan's report to the Legislature a few years ago was called *You've Got a Friend*. We need friends, and this legislation may perhaps help us find those friends.

Two summers ago I attended the longest coroner's inquest in Canadian history. I am the sole citizen, besides the jury, who endured the months of testimony about a place called Cedar Glen Boarding Home and the death of a man named Joseph Kendall. I urge you, I implore you: Do as that coroner's jury recommended and pass this legislation. I have been to too many inquests which made recommendations which were never acted upon.

There are headlines every day about the recession and the deficit, and I know that members of this committee must be concerned about what this is going to cost. It is hard to be precise. It looks like these proposals are going to cost millions. In hard times everyone becomes more vulnerable, especially those of us who are more vulnerable to start with. It will take time and talent, energy and money, to do the right thing right here. Please, try to ensure that there are adequate resources available so that this can be done right.

The Ontario division of CMHA is not a pro forma member of the Ontario Advocacy Coalition. That is to say, we do not send off a delegate; we send off a representative. Hundreds of hours and a few thousand dollars have been spent examining and discussing this proposed legislation in considerable depth and detail. Our policy advisory committee, our executive committee, board and staff have given a lot of thought and attention to this. Our rather slow but careful process has left us with something close to consensus, but we do have some differences with the OAC position on several issues. Carol will take you through the highlights of those points. I urge you again to read our brief later for details.

**Ms Roup:** My name is Carol Roup. I am the director of social policy and research for the Canadian Mental Health Association, Ontario division. Through 35 branches located across the province, a range of community mental health services and programs are provided by the CMHA to local communities. These services include employment, housing, social rehabilitation, case management, advocacy and public education. With advice and input from both staff and volunteers involved with the provision of these services, the Ontario division devotes considerable effort to ensuring that policies, practices and legislation respect the human and legal rights of people with mental disabilities. In this respect, the Ontario division board of directors places a high priority on the organization's role in systemic advocacy.

As we have made clear in our submission, our position is an active endorsement of the Ontario Advocacy Coalition's full brief. The amendments suggested by the coalition enhance the proposed legislation considerably and stand to place Ontario in a position of leadership in Canada with respect to progressive legislation. However, we do have two departures from the coalition's position which we feel we must bring to your attention today.

The first has to do with subsection 55(3) and section 57 which introduce the notion of partial guardianship. Our organization supports these sections of the bill as serving the needs of people who experience fluctuating incapacity to make personal decisions in specific areas and who may also have periods of incapacity over time. We believe partial guardianship enables a court to choose a less restrictive alternative than full guardianship.

The second departure from the OAC's position has to do with section 34, which deals with the issue of secrecy in respect of all information about a vulnerable person. Again, our organization supports this section of the bill and recommends there be no amendment. Our position here is that there is a danger in legislating the behaviour of

advocates and inadvertently portraying them as informants. The duty of the advocate is to respect the right of the individual to self-determination. We suggest that a policy or code of ethics established by the commission might further address this complex philosophical issue.

You have our submission, as Hugh has mentioned, so in the interests of time I will simply highlight a few additional points which we believe are important.

We believe that through the policies of the proposed commission the most vulnerable people should be our first priority.

We believe there need to be adequate resources available. Advocates, assessors, as well as staff of the public guardian and trustee's office will need to be on call seven days a week, 24 hours a day, if the schemes presented in the legislation are to serve the needs of vulnerable people.

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We believe the implementation of the Substitute Decisions Act and the Consent to Treatment Act should be delayed by a minimum of two years for the Advocacy Act to be fully and effectively implemented. This is to ensure that before the system is overwhelmed with demands for rights advice, the commission has time to establish sound policies, standards and procedures for the advocacy system.

We believe the importance of training needs to be emphasized. The successful implementation of all four pieces of legislation rests heavily on recruitment and specialized training of a multitude of professionals and others who will assume a critical role with respect to the very varied needs of vulnerable people.

We believe a broad-based education process should be undertaken by the lead ministries involved with the legislation and continued by the commission immediately upon its formation. This poses a considerable challenge, especially with respect to vulnerable people and cultural sensitivity.

Finally, we believe that once proclaimed, these acts have to be enforced, and that through the authority of the commission a simple but effective complaint system needs to be put in place.

**Mr Mancini:** I was interested, sir, to note the strength of your argument when you first started and kind of told us, but did not go into any specifics, that we had heard a lot of things that in your opinion were, if not factually incorrect, then maybe somewhat exaggerated in one way or another. I am very curious to know a little bit more specifically about that. Could you maybe take a moment to point specifically to one or two areas that you would consider to be matters we should hear?

**Mr Tapping:** You are really putting me on the spot, Mr Mancini. I am here as chair of a standing committee of an organization and you are asking me to switch that hat to my more traditional hat, namely, my own hat. This is a preface to my remarks, saying that I am not now speaking for the Canadian Mental Health Association; I am speaking for Hugh Tapping.

At age 16 I was diagnosed—I prefer the word “labelled”—schizophrenic, a particular version of it. I do not know if you are aware that there is actually a standing committee of the

American Psychiatric Association which defines these diseases. That is the rational basis for these things. Mine was incurable. I have had access to my medical records and I am overdue by about a decade now for a lobotomy and a permanent place in a back ward.

Among the things this morning that really shook me up was the assertion that science and scientific facts are somehow not ideological. I would ask anyone to read anything from high-school-level political science, sociology, even philosophy. That is just not true. Everything is ideological, ultimately, to ideologues.

I was very concerned with the general tone of "these incompetent people." I was very concerned that the condition which I purportedly suffer from—I would prefer the word "experience"—should somehow give me an out from the Charter of Rights and Freedoms. People are people. Some of us are not very competent at some things. Others of us—those of us, of course, who get elected to the Legislature—have to be competent at just about everything. I do not think I am that different from you. I know that in our society, that can often be a frightening thought if it is not presented carefully and with a bit of wit.

One other thing was with reference to science again and how it is scientifically proven and known. Well, I have a paper at home somewhere in the rubble of my desk by a psychiatrist, no less, from Colorado, I believe. He had a nice little grant for a few years. He went to the World Health Organization and looked at its data and its statistics. What he discovered, somewhat to his chagrin, was that nowhere else in the world is the outcome of this condition as bad as it is in our medicalized, high-tech western societies.

He goes on for pages about, "Are we talking about schizophrenia?" and yes, he buys this medical model of things. I know from my own considerable world travels that people do go crazy everywhere, often-times right at that stressful time of adolescence, early adulthood; no question. According to the World Health Organization, nobody does worse than us. The rest of the world, as long as it is not a medical intervention with drugs, electrodes, strapping people to their beds naked and alone, as long as we do not do that sort of thing, it seems things self-correct at a far greater rate than they do here. We must be doing something wrong.

**Mr J. Wilson:** Thank you for your presentation, of course. In much of it, admittedly, you agree with the Ontario Advocacy Coalition, but I am interested in this latter discussion. You heard Dr Cleghorn this morning saying that he would just as soon do away with form 1 and that it is really a burden on the medical profession that the state imposes on them to give them authority for involuntary admissions. Along that line, I would ask you, though, in your experience, is there never a case for involuntary admissions?

**Mr Tapping:** Mr Wilson, are you asking me, myself, or me as part of this deputation? Like I said, I am on the standby list. I would very much like this committee to talk to the clerk so that we can go into these things in greater detail.

**Mr J. Wilson:** Whatever way you feel comfortable.

**Mr Tapping:** As a democrat, I am obliged to act in a democratic manner and not speak for myself when I am here as a deputant for an agency and an organization.

The answer is that of course there is a need at times. I think it should be something better than how many beds are available tonight, which is all too often my experience. There is this wonderful paradigm of the locked door at the admitting ward and a crowd of people on both sides of it. There is a bunch of people saying, "Let me in, let me in," and they are being told, "No, you are not crazy enough." On the other side of the door there is a bunch of people saying, "Look, I know I am messed up, but this isn't what I want. Let me out of here," and they are told, "No, you're too crazy."

But to answer your question succinctly, yes, there is sometimes a need for help of a very careful and controlling kind.

**Mr J. Wilson:** Have you looked at ways we might be able to get rid of the form 1? Actually, today with Dr Cleghorn is the first time this committee has been told that other options have been suggested to the Ministry of Health over the years. In fact, we will ask for a briefing on that. Has your organization given any thought to perhaps a more humane way? I think it was alluded to during Dr Cleghorn's questioning that we get very black-and-white cases put to us. We do have people who appear who say, "Never, ever, ever." We have the middle of the road, but more extremes than we have people saying—particularly families. I have to admit that my own bias, coming from a family with someone who suffers from schizophrenia, is on the side of the families because I have just seen the horror that occurs, but I am trying to understand both sides.

**Ms Roup:** I will take that question. Our organization has not considered that because in fact this is the first time I have heard that put forward. We certainly might.

With respect to your question about whether there are times when people should be involuntary committed, I do not think anyone could disagree that there are times. The Mental Health Act adequately covers a provision that allows people to be involuntarily committed if they are a danger to themselves and others. We feel the Mental Health Act has taken care of that.

I know you have had evidence presented to you that the Mental Health Act is routinely ignored and that it is not a matter of the Mental Health Act not working as much as a matter, as Hugh has pointed out, of the number of beds available and the number of alternatives available in the community. A number of our branches are forced into individual advocacy simply because they are the only game in town. If adequate supports were available in the community, we might be able to avert some of those involuntary admissions, or at any rate avert family members feeling that their only out in the situation is to have their relatives committed.

I think our organization feels this legislation is supportive towards families not only in giving them priority as substitute decision-makers and guardian representatives, but also in that once we have advocates in the field, there

is quite a body of evidence to support the fact that there might be pressure on the system to build up the community alternatives, which would include family support.

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**Mr J. Wilson:** But on that point, there is a limited amount of money. We are already looking at rationing of health care. I have played devil's advocate and asked a lot of different groups, "Do you want the money spent on advocates?" because what if an advocate says, "Well, I need a bed"? It does not matter if the patient is saying that or the family is saying that or the advocate; it is not going to change things. The fact of the matter is we do not have beds. We do not have money.

So I do not understand, and I have been trying to for weeks. A lot of groups come, and I think the crux of the problem is we do not have the community resources. To add another layer in cost—I was going to say to the nurses, "Do you want more nurses or do you want advocates?" Someone has to bite the bullet in this society and make some tough decisions. We have had too much of promising everybody everything, and this legislation unfortunately gets caught up in that debate.

**Ms Roup:** I do not believe it is the role of an advocate to decide on whether somebody needs a bed or not.

**Mr J. Wilson:** But what if they are voicing that on behalf of someone who wants in the door, as you say? We do not have the money now, it seems. It seems pretty evident to me as Health critic that we do not have the money now to properly give the services that we say and that the World Health Organization says we should be providing.

**Ms Roup:** We are not convinced that once an advocacy system is in place the hospitals will be overwhelmed with a response for more beds.

**Ms Carter:** As regards advocacy, you say you subscribe fully to our vision of the role of advocates as respecting the right to self-determination by the individual. There is obviously no philosophical difference between us there, but you do not agree with the amendment that the Ontario Advocacy Coalition is suggesting.

What in your opinion should an advocate do if he comes across a person who is not capable of expressing his opinion but who obviously is being abused or is in trouble? I think the example sometimes given is somebody who is lying in sheets that are soaked with urine and is not being cared for properly, or if, for example, we come across somebody who is expressing suicidal tendencies. What do you think should happen in those instances?

**Mr Tapping:** Two parts, the latter first, and then I will ask you to remind me about the first one: If a person is saying, "I'm going to commit suicide," my experience is that the person who is going to commit suicide—and I have known too many of them—stops talking about that. They cheer up, actually. Everybody is really assured. "Oh, boy, the storm has finally broken" sort of thing. Then it turns out that, yes, the person has stopped complaining because he has made that irrevocable decision.

If a person is saying to someone who is in a position of perceived authority, "I'm going to kill myself," imagining

myself as that advocate, I am really stuck here. On the one hand, there is confidentiality. On the other hand, I am still a human being. When someone is crying out for help, I would hate to have a job that told me, "Nope, you can't do it, period." I like the way it is written, where the advocate "may" and the advocate "may to appropriate authorities" and so on. So let's leave it up to this Advocacy Commission—

**Ms Carter:** Discretion, yes.

**Mr Tapping:** —which we are establishing to figure out the guidelines and the policies, rather than enshrining it in legislation.

**Ms Carter:** Once you have rigid guidelines you remove that element of responding to the individual situation.

**Mr Tapping:** The advocacy that has happened over the years has not been adequate in many ways. There is always a threat or a danger that once you establish something and formalize it, it will become bureaucratized. I would see that as a probability, just because we are dealing with human beings, but I would be very concerned to put it in the legislation. You could end up with a very bureaucratic style process of—automatic; you do not have to think and you are not allowed to feel. I hope that after a few years the experiences of these advocates would probably modify, certainly codify, some of the things that would be done in the first few years.

**Ms Carter:** But they might get into trouble for breaching confidentiality.

**Mr Tapping:** So? If an advocate is not willing to get into trouble, an advocate is probably not quite doing the job the advocate should be doing. What was the first part of your question?

**Ms Carter:** If they find someone who cannot express their wishes but is obviously not being looked after properly, or abused in some way.

**Mr Tapping:** Oh, there is precedent for that. I mentioned the Cedar Glen inquest. That was exposed thanks to the psychiatric patient advocate office, which is explicitly prohibited from dealing with outpatients, discharged patients, as these people technically were. They were all from Queen Street and they were all parked off in an unincorporated village outside Orillia. The patient advocate office had no legal authority to do what it did, but it did it.

**Ms Carter:** So you do not want it put down in the legislation, but you do want it to happen on the judgement of the advocate.

**Mr Tapping:** I think I would like to turn this over.

**Ms Roup:** There are two parts to your question. The first part: We do not have a departure with the advocacy coalition. We are supporting both instructed and non-instructed advocacy. The second part of your question, which has to do with an advocate maintaining secrecy, is the part on which we have a departure but we are supporting non-instructed advocacy.

**Ms Akande:** I agree that if one person is at risk, it certainly demands that the system be addressed as it is being here. As a matter of fact, the O'Sullivan study commissioned by the Liberal government estimated that there

were about 1 million Ontarians who would need this service, so it seems it is most appropriate.

It seems to me that the hook many people are hung up on is the difficulty of implementing the whole process, the fact that it does indeed take time, especially for groups of people in need of immediate service and response. Do you have any ways—I know you have identified it as a difficulty for you—do you have any quick suggestions towards ways that might be implemented more expeditiously?

**Mr Tapping:** Father O'Sullivan's report had an awfully large number of people who potentially could use at some times, in some ways, some advocacy. My personal preference is something more along the lines of the volunteer fire department, or you go where the need is the greatest and start there, right? I would hate to think of trying to set up something that was looking at having a million clients in two years' time. Let's look at places like Cedar Glen. We know there are hundreds of places. There was testimony at coroner's court from an adult protective services worker that, "Well, it was pretty bad but I have seen lots worse."

**Ms Akande:** Would it not be wise—

**Mr Tapping:** Let's go there. Let's focus on where the need is greatest, where there is—and check your Hansard about questions to the minister. Check the databases from the press and the media. There are problems out there already that keep coming up at the level of coroner's court: life and death foulups. Let's focus in on that as a beginning. If this Advocacy Commission, as it is proposed it be constituted, is allowed to have the power to decide such things, I think that would arise out of the way the legislation is written now. In a way, in spite of the government money, it is almost a self-help model where the people who are most involved are going to be the ones right in the planning and execution of this.

**The Chair:** Ms Roup, Mr Tapping, on behalf of this committee I would like to thank you for taking the time out this morning and giving us your presentation.

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#### MENTAL HEALTH CENTRE OF PENETANGUISHENE

**The Chair:** I would like to call forward our next presenter from the Mental Health Centre of Penetanguishene. Good morning. Just a reminder that you will be allowed a half-hour for your presentation; the committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each caucus. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Dr Fleming:** My name is Russ Fleming. I am a psychiatrist. I grew up in southwestern Ontario. I attended the University of Western Ontario, graduating first in honours science in 1965 and then in medicine in 1969. I have been a qualified practitioner of medicine in this province since 1970 and a qualified psychiatrist and a fellow of the Royal College of Physicians and Surgeons since 1975. I have worked for the past 18 years at the Mental Health Centre of Penetanguishene. I am currently the psychiatrist-in-chief there since 1989. I am by experience a forensic subspecialist.

I appreciate very much the opportunity to address the committee this morning. I apologize in advance because I am sure that some of what I am going to say you have already heard from previous presenters. I intend to focus on one specific area in Bill 109, that of prior wishes or instructions and the function of the Consent and Capacity Review Board in relation to that issue. I am the Fleming in *Fleming v Reid* and *Fleming v Gallagher*, which sounds disturbingly adversarial if you know that both Reid and Gallagher were patients under my care.

The Reid and Gallagher story can be found in detail in the Ontario Reports, third series, volume 4, September 1991. It details the decision of the Court of Appeal for Ontario from June 28, 1991, where section 35a and subclause 35(2)(b)(ii) of the Mental Health Act of Ontario are declared "inoperative in so far as the sections purport to empower the review board to authorize the psychiatric treatment of incompetent patients involuntarily confined in psychiatric facilities contrary to the refusal of the patient's substitute decision-maker to consent to such treatment on the basis of the patient's prior competent wishes."

In somewhat simpler terms what this appears to mean, at least for the present, is that once people suffering from schizophrenia have declared their opposition to treatment at a time when they were competent to do so, or at least apparently competent to do so, then they can never be treated again. This is particularly significant and I think tragic for an illness of such major proportions which usually has lifelong implications.

In addition to demonstrating that the result can be unsatisfactory, I also wish to give some indication of how complex and time consuming these proceedings can be. I am therefore going to provide you with some detail in regard to one of the cases in particular, that of Gallagher. I am in part borrowing from the Ontario Reports summary.

The story begins in the early part of 1987 when we had in our hospital, in the maximum security division, two patients, Reid and Gallagher. There is nothing really unusual about their clinical situations except to say that both had a major mental disorder. Both at that point had relapsed into illness, both were considered incompetent to consent to treatment, and neither had available a substitute consentor. Accordingly, review board treatment orders were applied for.

The initial treatment orders were obtained in early 1987 without particular difficulty. However, around this time, through means which remain unclear to me, both of these patients came to be represented by the same lawyer who undertook to defend their right not to be treated, and therefore to remain ill and incarcerated. Both of the treatment orders were therefore immediately appealed and no treatment could then be started.

Before the appeals could actually be heard, the 1987 amendments to the Mental Health Act came in at the end of June of that year, and we agreed to abandon the treatment orders and to start over under the new and altered rules. It took some time actually to figure out how these new procedures would work. I started again to work on the case of Reid in the fall of 1987. Without going into extensive detail, it took from then until April 1989 to actually

undertake any treatment, at which time this patient had been continuously and floridly psychotic for more than 27 months. Even then, treatment was only able to be started on an interim order by a judge of the Supreme Court of Ontario after the patient's physical as well as mental condition began to deteriorate to a dangerous degree.

In the case of Gallagher, we did not attempt to further a treatment order until the summer of 1988, essentially because the lawyer indicated that our efforts would be fruitless in any event because any order obtained would simply be appealed. However, by the summer of 1988 the patient had regressed to such a degree that even his lawyer could apparently no longer communicate with him in any meaningful way. An application was made for a treatment order and an order for treatment with neuroleptic was provided for a period of three months.

Mr Gallagher's condition substantially improved during this time, but when the order ran out, he refused to continue treatment any further. A decision then had to be made as to whether or not we would apply for an extension of the treatment order. But, of course, by this time his lawyer had once again entered the scene, indicating that all possible efforts would be made to avoid him having any further treatment. Because I fully expected that he would relapse, and he insisted that he would not, we were able to reach an agreement with him to conduct a series of videotape interviews so that he could later review this for himself, because he in fact did not believe that he was ill or that he would relapse.

Over the next several weeks the patient underwent, as expected, a gradual deterioration and by February 1989 we were once again launched into an application for a treatment order. This was finally achieved but then immediately appealed, and the patient continued untreated. The appeal of Mr Gallagher's treatment order was finally heard in district court, along with that of Reid, on May 9, 1990.

In the meantime, we had sought an interim order for Mr Gallagher from Judge Tobias and this he had provided on April 4, 1990. However, with the handing down of his decision on May 9, this order no longer had any effect and treatment once again had to be delayed. However, a subsequent motion before Mr Justice Holden of the Supreme Court on June 22, 1990, restored this order.

The other side countered with a motion on July 11, 1990, to have this stopped, pending an actual appeal of the issue. This was dismissed by Associate Chief Justice Morden of the Court of Appeal. On September 4, 1990, a three-judge panel of the Court of Appeal dismissed the motion, set aside the June 22, 1990, order of Judge Holden. The treatment then was able to continue until the definitive decision upon the treatment order issued by the Court of Appeal, as I have said, on June 28, 1991. What this meant, of course, for Mr Gallagher is that his treatment had to be discontinued, and as on prior occasions, his mental state deteriorated. He remains at this moment chronically ill and within the maximum security unit.

There is, of course, one further disturbing detail. Because of the clear separation of matters of treatment from those of legal detention due to dangerousness, Mr Gallagher at this point appears to have inadvertently sen-

tenced himself to indeterminate incarceration. Because of his mental state, he lacks the capacity to understand exactly how this has happened to him. He is presently subject to detention under a warrant of the Lieutenant Governor, and even if that detention were to be discontinued due to capping provisions contained in the Criminal Code amendments, Bill C-30, he would not be releasable in an untreated condition. Because of his potential for dangerous behaviour in the community, he would have to be detained subject to the civil commitment criteria contained in the Mental Health Act.

In retrospect, I think a compelling argument could be made that at some earlier time, when Mr Gallagher made his determination that he would refuse psychiatric treatment, he was not fully informed of the potential consequences of such a decision. Perhaps at that point the consequences could not even have been foreseen by anyone. Unfortunately Mr Gallagher was also at some earlier stage led to believe that changes in the law, particularly Bill C-30, would automatically effect his release.

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His anger in that regard is understandably directed at those closest to him; that is, the clinical staff in charge of his day-to-day care. Those clinical staff, of course, being largely of sound mind, know to whom they should direct their anger, and that is to the legislators. Unfortunately the frustration and lowered staff morale which result are a chronic problem.

On a brighter side, there is a recommended solution contained in the Reid-Gallagher decision. Reading page 94 in the Ontario Reports, the third paragraph, we find the following wisdom from the Court of Appeal:

"In my view no objection can be taken to procedural requirements designed to determine more accurately the intended effect or scope of an incompetent patient's prior competent wishes or instructions. As the act now stands, the substitute consent-giver's decision must be governed by wishes which may range from an isolated or casual statement of refusal to reliable and informed instructions based on the patient's knowledge of the effect of the drug on him or her. Furthermore there may be questions as to the clarity or currency of the wishes, their applicability to the patient's present circumstances, and whether they have been revoked or revised by subsequent wishes or subsequently accepted treatment program. The resolution of questions of this nature is patently a matter for legislative action."

On page 95 the following:

"It is not for the court to rewrite the act and invest a tribunal with jurisdiction not given to it by the Legislature. Nor is it for the court to determine the procedure or criteria to be followed in making treatment decisions for mentally disabled patients. These are issues which involve governmental policy."

Within Bill 109 there is an opportunity for you, the current legislators, to resolve the problem of Mr Gallagher and others like him. It seems to me that when a decision to refuse treatment can have such grave ramifications, then it ought to be treated as having the same importance as decisions of informed consent. Then if a review panel decides

that an individual had all the information available in regard to the benefits and also the consequences of not having treatment, and was capable of weighing that information, then we will be happy to live with the result. I hope there have already been some attempts at such a revision, and since I am not a lawyer I am not going to attempt to confuse you with my version of what that might be.

In conclusion, as one who has had some experience with complex legislation of this kind, I think there will be two overall results of these new bills which will be unfortunate. First of all, because of the complexity of the procedures, practitioners will first of all tend to ignore the rules and a remarkable number of patients or clients will be regarded as competent. The test which will be applied unofficially is the one frequently used with our current Mental Health Act: If the patient accepts the treatment, the patient is competent; and, folks, that is not the test.

The second and perhaps more unfortunate result will be that practitioners, if they have the option, will contrive to avoid those clients who are obviously incompetent, to save themselves the confusion and frustration of dealing with the process. The patients or clients, of course, will be the ultimate losers in that.

Finally, it seems to me that at a time when we are just beginning to come to grips with the extraordinary costs involved in the delivery of health care, it is disheartening to realize that we are about to spend an as-yet-undisclosed amount of money on a system which in reality will result in no demonstrable net benefit to the clientele. I wonder how much more we could have accomplished if we had applied the same money to schizophrenia research.

I am going to add one more comment that arises out of an issue or two that were raised here. This ongoing debate between the medical model and the psychiatric power on the one hand, and anti-psychiatry and patients' rights movements on the other is non-productive. If you want to find out, if this book has not been recommended to you, read this: It analyses very clearly what the debate is about and it also says there is no future in continuing the debate. What we have to do is forge an agreement by partisan consensus about what ought to be done.

In that regard, people on the psychiatry side of things have to acknowledge—and we do, I think, for the most part—that there have been abuses in the past and there are abuses now and that those abuses do not finally get solved by advocacy. They get resolved by good, solid, sensitive management of the system by systems managers, and that is one of the great deficits we have had. We have not had people in the system who could actually manage, for example, a psychiatric hospital in a way that made sure that abuses, at least, were minimized as far as they can be.

On the other hand, we have to reach out to the people who appear to be preoccupied with those abuses and preoccupied with legal and power issues, and keep the dialogue going in terms of what will really help people in the long run.

Frankly, with the experience I have had with the Mental Health Act of Ontario, and as I listened to the discussion this morning, I think the rational thing to do would be not to scrap these bills, but to take a step back from them

and have a look at the Mental Health Act, amend it and make it work, because it does not work at the moment. Having done that, we would have a clear experience on which we could then go forward, because some of the principles contained in this legislation are indeed very important and ought to be carried through.

**Mr Mancini:** I have a very short question before our critic asks her questions. When these two gentlemen you were referring to were able to receive treatment, what kind of treatment were they given?

**Dr Fleming:** They were treated with medication, neuroleptics specific for schizophrenia and they both improved.

**Mr Mancini:** Anything else?

**Dr Fleming:** They were offered all the ancillary things that we usually offer in a hospital: supportive psychotherapy and counselling, participation in various programs, depending on their level of ability to participate, all of which helps as well.

**Mr Mancini:** So it was basically the drugs they objected to?

**Dr Fleming:** I guess it is the drugs. It is also an issue of being locked in a situation which they would rather be out of, feeling oppressed by that, features of their illness in which their suspicion and anger are very evident but not really connected with anything in reality. As far as the medications are concerned—

**Mr Mancini:** You do not think maybe they were fighting something else that was going on?

**Dr Fleming:** I am sorry?

**Mr Mancini:** You do not think maybe this was a way of fighting something else that was going on or bothering them? This was the only way to do it?

**Dr Fleming:** Well, I lived with these particular individuals on a week-by-week basis. I had a lot of time with them. These people had schizophrenia. Their cognitive abilities were seriously impaired by what was clearly an illness, and there were lots of opportunities to have those discussions with them. When they were on medications, and they were improving in terms of acute symptoms, the discussions I had with them on those occasions were pretty rational.

In the one situation, we had a series of videotaped interviews with Mr Gallagher; every week we would get the camera set up and have our videotape session. The purpose of that was to demonstrate to him, finally, that in spite of all the other things we were attempting to do for him, without the medication he deteriorated. We predicted that; we predicted it again; it happened again. I have been through that with other patients. That is the point that has to be made. There are some people who are really sick, and as a result of the sickness, they are really disturbed and really dangerous. No question about that. They deserve just as much appropriate attention and clinical care as anyone else, and that is what we strive to provide.

**Mrs Sullivan:** I appreciate your being here, because I think all of us have read about these cases in the past, and it is interesting to have you before the committee, having actually experienced the situation. We understand from

other presentations—I think of one from R. A. Stradiotto and one from Dan Ferguson, who spoke about the effects of this legislation indeed complicating and adding to potential litigation. Earlier today, the Ontario Friends of Schizophrenics suggested that a continuing power of attorney may be an answer with consequent and necessary alterations to the Mental Health Act, and may be a way to ensure that appropriate consent is given by the patient while the patient is in a lucid or coherent state, when that patient can understand not only the course of treatment but the risks attached to the treatment and the risks of refusing the treatment.

Do you concur with that proposal, and if we go back to the two cases you have illustrated for us today, do you think if that had been legislated at the time there would have been a difference in approach in dealing with those two patients and indeed a difference in the outcomes for those patients?

**Dr Fleming:** Yes, I think in principle that would be helpful. You cannot, however, rely on a substantial number of families or individuals to really undertake that sort of process. The more I engage in these discussions and the more I wrestle with our current rules, particularly the Mental Health Act, the more I wonder if even somebody like me personally ought to put down somewhere now how I should be handled when I get my profound depression and when I go crazy, because do you know what my fear is about our current system? My fear is that I will be handled badly by it. If I became paranoid and resistant to treatment when I was clearly ill, I would hope that my wife would give the consent for what is required for my care. But if I did not have a wife or I did not have anybody else to take charge, I can assure you that I would know what lawyers to get and how to use the current system and I would never have treatment, and that would be, I think, a tragedy.

That is what I think is very wrong with the way we are currently approaching this. There are people who need treatment who do not get it when they should, because of the preoccupation with following legal rules. I am perfectly in favour of having legal rules to follow. I am also in favour of making sure that people follow them. At the moment, they are not. I do not want to go into the examples of that, but people do not follow the rules of the Mental Health Act right now. In the vast majority of general hospital units in this province they do not follow the rules.

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**Mr Sterling:** I assume in your institution you have an advocate now. How is that working out?

**Dr Fleming:** It is working out very well at the moment, but it has taken eight years to reach the point we are at now. The advocacy system goes back to 1983.

**Mr Sterling:** Yes.

**Dr Fleming:** The first advocates were chosen specifically because of their hard-nosed, anti-psychiatry basis. They came into the system to fight with us, so we fought with them. I fought with them, because I thought that was what the game was at that point. Things mellowed. I have

mellowed to some degree because I do not fight with them any more; there is no future in that.

I think the job of being an advocate is a lot more complex than people first understood it to be. The job of being an advocate is not to be an adversary to the system; it is to be a helpful, critical, but constructively critical facilitator, and one of the people we have now particularly is the best one we have ever had. He does not back away from issues, but he also does not come into your office and cause you annoyance when you have 18 other things on your plate, just because he has got some minor point to make.

**Mr Sterling:** I do not know if you have looked in any detail at Bill 74, but one of the concerns I have is that it is built into the legislation that it is partisan. The advocacy groups told me that in particular and they support that. I guess one concern I have with regard to the advocacy bill is that if there is a complaint from a health care giver like yourself or a complaint from a parent or a close person who is a friend or whatever of a patient, there is nowhere to go. If an advocate is stepping out of line or is not properly trained, there is no complaint procedure within Bill 74 to deal with that.

**Dr Fleming:** I have not looked at that carefully, but that would be of concern, as I have said. I think being an advocate is a very complex job which has legal and clinical implications, and people in that job are not going to do it perfectly either. It seems to me there is something wrong with a system where in all the other clinical disciplines, from medicine through nursing to occupational therapist through the whole list, the vast majority have a licensing body to whom patients can complain about the best medical practitioner in the system, if they choose to complain, and that complaint will be followed up on. Why would we then give another group of people the kind of power this advocacy system would provide without some reasonable checks and balances on how they conduct their operations?

**Mr Sterling:** On page 14 of your brief you say, "It seems to me that when a decision to refuse treatment"—this is under Bill 109—"can have such grave ramifications, then it ought to be treated as having the same importance as decisions of informed consent." Then you go on to talk about the review panel dealing with those two issues. Are you suggesting that the health care provider on the spot make that decision and then the decision is reviewed by the panel, or are you suggesting that the treatment be delayed until the panel reviews the situation?

**Dr Fleming:** The treatment would be delayed, there is no question about that, but if you take the situation of Gallagher, because that is what this is about, all I want to be able to do now is reopen the issue with a review board and examine at what point in the history the decision was made by him that he would not have treatment, and have the review board have the power to examine what information he had. What was his capacity, as far as we could tell at that point, to make a rational judgement about it?

The reason you arrive at the stage of making a review board application is that all other consenters have declined to provide consent, and the last of those of course is the office of the official guardian within the current rules, and

the official guardian's office will give you consent so long as it can find no other evidence, not the slightest shred of evidence, that there was a prior wish when the patient was competent. As soon as they find the slightest indication that there was a prior wish, and it can be as simple as a single line in a clinical record or a single statement on some occasion, then they will not give you consent because there is a prior wish. In the previous system, you could still have the review board override that by providing a consent.

What this decision has done is take that away, and there has to be some redress of that. A review board would be the logical group, it seems to me, to have the power to re-examine that issue retrospectively, and if it determines that the person was clearly competent and clearly decided he did not want this sort of treatment, then that is fine; we live with that. But I do not think, frankly, in the case of Gallagher that there was anywhere near a proper opportunity for him to really look at that issue.

The other thing of course is that in an illness like schizophrenia, where one of the features is that people do not realize they have it and they remain uninsightful, sometimes for their entire life—they just do not believe there is anything wrong with them—a fairly compelling argument can be made that they may not be competent from the first moment the illness onsets.

**Mr Wessinger:** I would just like to ask you a question. Does the Consent to Treatment Act make any change with respect to the principles that are presently in the Mental Health Act, or is it basically consistent with—

**Dr Fleming:** It is basically the same. I have not read it in detail lately, but it tidied up one thing that is a problem in the Mental Health Act, and that is the issue of applications for review of competency. In the new rules, there will be a limitation on when a patient can actually reapply once a finding of incompetency has been made. What some of our patients did was apply every week until we kind of said, "Wait a minute, we just had a hearing last week and nothing's really changed," and the review board, in its wisdom, said: "Yes, this does appear to abuse our process, so we won't hold a hearing right now. Apply again after a while if you think there's some change in your capacity." That was a flaw in the Mental Health Act and that has been fixed.

1210

**Mr Wessinger:** This will be an improvement then.

**Dr Fleming:** Yes.

**Mr Wessinger:** In the question of prior wishes, it has been suggested sometimes by certain groups that a pre-validated power of attorney would be useful. Would you find that useful in your circumstances?

**Dr Fleming:** Yes, I think so, in some cases.

**Ms Carter:** Dr Fleming, it seems from what you said that in the case of Reid and Gallagher, certainly the improvement resulting from medication was dramatic.

**Dr Fleming:** Yes.

**Ms Carter:** So obviously medication does help some people considerably, but are there some patients who are not helped by medicines in the same way?

**Dr Fleming:** Yes. It is not a large number, but there are some people with schizophrenia who do not respond well to anything. In fact, some do not respond at all. Those people we manage in hospital, if we are required to, by whatever means we need, and the nursing staff can in fact be quite creative in terms of finding ways to live with those individuals in a reasonably humane and amicable way. It is impressive sometimes how well people can be managed even though they are absolutely out of touch.

The difficulty I have encountered—and I have been through this with other patients—is that some patients, as they are working on the issue of the illness and the fact that they have it, need to test and retest the issue of medication and whether they will relapse without it. I have had patients where we have gone through the process as much as four times. They are in a secure environment. They say: "I realize I'm pretty well now. I'm on this medication. I'd like to stop it and see what happens." I say, "Well, it's a safe environment; we stop."

Over a period of weeks or months they relapse, we put them back on, they come back to a stage of reasonable wellness, and I say, "You know, it looks as though it happened again." "Well, maybe that was a fluke. I'd like to try it one more time." We go off again; they relapse again. This is the process of working through with someone who has this sort of problem, and those patients all finally say, "I don't like the side-effects and I don't like some of the things it does to me, but if we can keep the dose to a minimal level and minimize the side-effects with the side-effect medication, I guess it's the best choice I have, because it is not a perfect world," and away they go, and they disappear back into the world.

**Ms Carter:** Could there not be some patients who find the subjective effects of medication so unpleasant or overwhelming that they really have a basis for saying that they would prefer not to be on medication?

**Dr Fleming:** Yes. It is an individually variable thing. Some people are very sensitive to medications. What can be done then is to try other medications, because these days we have some drugs in which the side-effect problem is much less acute, drugs like pimozide, which is said to have much less in the way of the traditional side-effects. The current wonder drug being much discussed, clozapine, is said to be a better drug in terms of side-effects. It is also, interestingly, a drug that is said to be effective in about one third of that group which is completely unresponsive or intractable in terms of the other drugs, and of course what the drug experts tell us is that clozapine is just the first of a series of other drugs that will be developed over the next few years which will have an even better profile in terms of side-effects and not the risks of things like agranulocytosis that is presented with clozapine.

I think it is really unfortunate to be, on the one hand, building a set of rules that may prevent some patients—my guy Gallagher cannot get treated now. He cannot get clozapine. He cannot really get anything that will actually help him. In what other circumstance would we accept that someone is incarcerated for five or six years in a maxi-

mum security setting and say, "Well, I guess that's the way the world is"?"

**Mr Sterling:** Mr Chair, with your indulgence, could I just ask, in Penetanguishene, what percentage of the residents there would be suffering from schizophrenia versus other disorders?

**Dr Fleming:** Two thirds to three quarters would have a diagnosis of schizophrenia in the maximum security unit, I guess.

**Mr Sterling:** And in other institutions in the province, do you what the figures would be there?

**Dr Fleming:** It would be a lesser percentage, but it is a high percentage. Schizophrenia is a very common illness, relatively speaking; 1% of the population through all cultures at some point in their life will have at least one acute schizophrenic form episode. That makes it a pretty common problem.

**The Acting Chair (Mr Poirier):** Dr Fleming, on behalf of all of us, thank you very much for coming forward. This committee stands adjourned until 1:30.

The committee recessed at 1216.

## AFTERNOON SITTING

The committee resumed at 1350.

HEALTH SCIENCES CENTRE,  
UNIVERSITY OF WESTERN ONTARIO

**The Chair:** I call this meeting to order. I would like to call forward our next presenter, Dr Bessie Borwein. Good afternoon. I would just remind you that you will be allowed a half-hour for your presentation. The committee would appreciate it if you keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Dr Borwein:** Thank you. First I would like to say how much I appreciate the process that is in place here today and to thank you for the opportunity to make a presentation. I am Dr Bessie Borwein. I am here to address you particularly about matters pertaining to research and somewhat about other things.

I have three roles in my work. I am the associate dean, research, for the faculty of medicine, I chair the university's review board for all health research involving human subjects and I also chair the university-wide biosafety committee. My professional appointment is as an associate professor of anatomy with a cross-appointment in ophthalmology.

Our main concern is with section 15, paragraph 1, of Bill 109, and there are also references that pertain in Bill 108, subsections 47(6) and 56(5). The wording in Bill 109 says, "Nothing in this act authorizes a health practitioner to perform any of the following procedures on a person who is incapable with respect to the procedure," and paragraph 1 describes this as, "A procedure whose primary purpose is research." The statement is reinforced by item 6 in the explanatory notes, which refers to "research procedures, non-therapeutic sterilization and the removal of tissue for transplants." The latter two procedures are illegal. Research is far from illegal, yet research procedures have been associated with these, putting research into, as you might say, illegal company.

Since nothing in the act authorizes a research procedure, the statement is very vulnerable to interpretation as prohibiting, especially in light of the *E. (Mrs) v. Eve* decision of the Supreme Court of Canada in 1986, which was rapidly generalized in several domains to apply to all non-therapeutic research on vulnerable populations.

I would like to take some time here to describe to you the process of ethical review at the University of Western Ontario. I think we are fairly unique in that the entire community in London has the ethical review for health sciences pass through one review board. That is all the hospitals and the university and any of the organizations in the area who request us to do it for courtesy reasons.

Our review board permits research on vulnerable populations, but only under very stringent conditions. I might like to add as an aside that the very process of research, the sophistication of it, its concerns with the social and ethical counterparts and issues have dramatically become more

sophisticated in the last 30 or 40 or 50 years, but almost all of it without legislation. It has grown up through process, and much of what we do is under guidelines and codes.

We had decided, after a lot of discussion, that research on vulnerable populations under certain conditions had to proceed, because to prohibit all such research was to withhold from those populations the possibility of the alleviation of their illnesses and disabilities, which we consider to be unethical. Should such a prohibition on all research with those who cannot themselves give informed consent ever be enforced, the research and the researchers would indeed move to other provinces and other countries where this would be permitted, and of course in some countries the ethical research standards are far below those in Canada.

The position adopted by the review board was publicly described and discussed at length at a conference of the National Council on Bioethics in Human Research in Canada four years ago. There is much greater value in guidelines over legislation, because guidelines allow for greater flexibility and a more rapid evolution, drawing on experience and evolving societal needs and standards, and there is a more rapid opportunity to adapt, learning from different ways of doing things. Often in ethical issues there is not only one right way to proceed. After due investigation of the issues and considered deliberations, informed judgement is brought to bear on the decision that reasonable people can agree with. The crucial elements in making ethical decisions include these careful deliberations and the consideration of various opinions.

In our society there is little moral absolutism. Lady Mary Warnock, mistress of Girton College, Cambridge, was chairman of the Committee of Enquiry into Human Fertilization and Embryology in Britain and wrote the much-respected Warnock report, apropos which I thought she said two very important things: One is that the law should beware of following the ideals of extremists and the other is the injunction to not allow moral fantasy to take precedence over realism.

I have appended to my submission the documents which are guidelines that are in use at the university. We do exactly the same kind of review for Madame Vanier Children's Services, the Children's Psychiatric Research Institute, the Thames Valley Children's Treatment Centre and any other group that so requests it of us. The primary mandate in all our reviews is exactly the same: It is the protection of the participants in research.

I draw your attention to particular sections of our guidelines, which deal with the very difficult problems of principles of consent, informed consent, exceptions to prior informed consent, subjects who are incapable of giving informed consent, research on children and research involving incompetent adults, all of which we have addressed in great detail—not ourselves alone; we have drawn clearly on world expertise on this as well. I submit this information because it demonstrates the restrictive and stringent approach taken without the intervention of specific

legislation and without recourse to setting up of an expensive and bureaucratic paid advocates approach.

The second addendum is the report prepared by us for the site visit of the three people who were appointed by the national council on bioethics to visit our university and assess our operation. They are doing these site visits across Canada. That document summarizes how we work and how effective, careful and onerous is the operation. It is also very economical, because it works very predominantly on volunteer labour. Included in that addendum is a letter sent to all the deans and chairmen of departments within the university, by the vice-provost health sciences and myself as chairman of the review board. I would like to read to you part of it. The letter reads:

"Service on the review board for health sciences research involving human subjects demands a very substantial commitment of time. The board meets for a minimum of three hours once every two weeks during the year.... Every member of the board (there are 16) is required to read carefully an average of 20 protocols in preparation for each meeting." It requires up to about six hours of reading time. "At the time of grant submission deadlines, the number of protocols reviewed at one meeting might number closer to 30. In addition, members accept assignments from the board to discuss protocol problems with researchers and to review drug company submissions and any other pertinent documents.

"The workload makes such a heavy demand on time and contributes so importantly to the integrity of research, the maintenance of research standards and the reputation of the university that special recognition should be accorded to those who serve on the board. When they are assessed for promotion and tenure and for merit, it is urged that services on the board be regarded as a very significant contribution to research and service in the university and the appropriate recognition be accorded."

In that context, I would like to tell you that at the moment every single one of the 16 members of the board has an alternate, so that somebody must be present at each meeting. We have a full complement. Four of the people presently serving on the board are not part of the university, and there are numbers of people on the board who are not scientists and not related to the health sciences. They come from other areas of the university.

I have also appended the protocol form on which submissions must be submitted. No other form is acceptable and no research can commence until writing and approval is granted.

Again I would like to emphasize that our review board functions very well. We got a very high praise from the site-visiting team. We do it without legislation. I think it is important that these ways in which we function should be made known, because a good deal of anxieties often arise from inadequate information or misinformation.

1400

I would specifically like to address the value of research on vulnerable populations, especially those who cannot themselves give informed consent. To proscribe or even very seriously curtail research on these people, we believe, is unethical. It discriminates against them with regard to

advances in the prevention, control, alleviation, treatment and cure of conditions that afflict them, and which advances are available to those who can give consent. It would also potentially expose these vulnerable populations to the introduction of treatments that have been inadequately tried and tested.

Some of the advances that would not have been possible without research on people who cannot themselves give informed consent and that have been of great benefit to them and other constituencies to which they belong include, for example, childhood leukaemias, many of which can now be cured. That is a fairly recent advance that would not have been possible without the ability to do research on children. We have treatments for the optimum alleviation of asthma; improved anaesthesia; far better treatment for the head injured, the great majority of whom are young people; the understanding of drug reactions, which are different in infants, children and adults and need careful clinical evaluations; treatment for neurological conditions; strategies for improving the conditions of mental retardation, and the treatment of cystic fibrosis, the single biggest genetic disease in Caucasian populations. There are new treatments for the control of juvenile diabetes. In addition, all the neurological degenerative diseases which are becoming more predominant in our society because of an aging population, such as the muscular neuropathies, amyotrophic lateral sclerosis, Parkinson's and Alzheimer's dementia, the dementia associated with AIDS, and schizophrenia are all desperately in need of more research.

I would like to address you from personal experience on the subject of Alzheimer's. My mother, a patient, gentle, polite woman, suffered a most terrible deterioration through 10 years of Alzheimer's disease. It transformed her into somebody who would hit other people and say outrageous things to them. It was a relentless disease. She did get good treatment in a nursing home in London. Of course, no nursing home and no treatment is good enough for your own mother, but given the circumstances, she was well treated there. But the disease is so relentless that nothing you do alleviates the progress of that illness. The only hope is research. The only hope is drugs to control it and the understanding to prevent it.

I append a letter from an eminent psychiatrist in London, Dr Harold Merskey, an internationally known authority in the field of studies of pain. His letter deals specifically with some of the mentally disabling conditions. In Ontario there is significant research on Alzheimer's disease and schizophrenia. We feel sure that it is not the deliberate intention of the government to suppress this research, but that would or could or might happen if section 15, paragraph 1, were enacted.

I would like to add the strong support of the UWO faculty of medicine for Dr Lowy's submission on February 12 and support his concerns about portions of Bills 74, 108 and 109, and also those of Dr Bernard Dickens and Dr Eric Meslin of the same date. I particularly wish to quote from Dr Lowy on pages 3 and 4, where he says that "...unfortunately in our view these bills as drafted contain serious shortcomings. These are of such magnitude that, unless

they are corrected, there is a risk that the legislation which is so well intended may do more harm than good."

I would also like to, in a context a little bit away from research but certainly impinging on it, quote from the submission made to you by my friend in London, Ontario, Mrs Pat Chefurka, a previous president of the NDP in Ontario. Again, I would like to quote from her submission: "The freedom to be insane is an illusory freedom, a cruel hoax perpetrated on those who cannot think clearly by those who will not think clearly."

I can only end by saying that in the difficult area of ethics and morality, there is no absolutism, and there will never be perfection in a multifaceted society. But we can ask that the most careful consideration be given, that well-intentioned people dwell on this and that we use the opportunities of the family structure to participate in all these decisions, because imperfect as it is, like democracy, it still is the best institution we have for the protection of people.

On behalf of the faculty of medicine and the review board for health sciences research involving human subjects at the University of Western Ontario, I request that paragraph 1 of section 15 in Bill 109 and the equivalent clauses in the other bill be deleted. I want to thank you for this opportunity.

**The Chair:** We have five minutes for each caucus.

**Mrs Sullivan:** I am particularly appreciative of this recommendation and your intervention today. I think this is one area I have been concerned about from the beginning in relationship to these bills. I look at teaching hospitals, advances in medical science and treatment of patients, with the consent as it has been done in the past of either the patient or his or her representative, whether it is family or friends, and see significant advances. Then I also talk to people who, by example, now deal with Alzheimer's cases and who say that if the bill is carried out in the way that it is written, Alzheimer's research would be set back by 20 years, and it would be incumbent upon us in our age group to make a decision now to allow the research to take place some 20 years down the line, assuming that a certain percentage of us will be Alzheimer's patients at some point.

The protocols which are used at the University of Western Ontario and in other faculties of medicine and teaching hospitals have been developed over a period of time through legal medical ethics committees. Under the common law now, do your practitioners feel they are legally protected in cases where there is not a consent either from the patient or from next of kin or a patient's representative?

**Dr Borwein:** I think you have touched on a very interesting and important area. We always have two legal representatives on our review board. Since I have been with the board, nearly five years, every decision we have taken has been reached by consensus. The advice given by the lawyers is excellent advice, but it does tend to be legalistic, and we listen very carefully.

But on the other hand, there are some things we would not do if we were only concerned about protecting ourselves legally. We believe that would be unethical. Again, like in many different difficult areas, we have to weigh and balance. We have to say, "Yes, we are taking a small risk,

but we are taking it." If you have a patient brought in who clearly cannot give consent and whose next of kin is not there with him or he does not have a next of kin, and yet you know that the evaluation you are doing has the potential of doing good for that patient, will you deprive him of it?

We do not allow any research in which nobody gives consent, but we do extend the range of those parties who may give surrogate consent pro tem because we ask for consent to be acquired from the next of kin or the patients themselves within 24 hours, and that surrogate consent must be taken in the presence of other people so it can be validated. But, yes, you are right, we cannot always be 100% legally protected; we know that.

**Mrs Sullivan:** There is some misunderstanding, and certainly my initial reading was a misunderstanding, of what is in this bill in terms of the tissue gifts. My understanding now is that paragraph 3 of section 15 is in fact the current practice and so on.

Another area, however, that I have concern in relates to consent in situations where there would be organ donations, whether for transplants or to participate, which may certainly be involved in a research program but may not be as well. I think Mr Fram will remember that at the beginning I raised that issue, and we were told that Dr Weisstub was conducting another investigation in this area and that we would see substantial and substantive amendments put forward as these bills were being considered.

That was the last time we heard anything about this entire issue of either research or tissue gifts. I hope that perhaps the parliamentary assistant, the minister or Dr Fram will be coming forward at some point with some further clarification and that there will be an appropriate consultative period so that those who are involved in the area will also have a chance to contribute to the process and a drafting of appropriate legislation.

**Dr Borwein:** There are differences between the biological understanding of organs and organs as understood in some of the—because blood is an organ of the body and blood is donated. We freely donate blood. However, we do not allow, I think wisely, any organ donations from living people, but we do allow people to make a gift of a kidney or a gift of bone marrow to a brother, for example. We have very difficult areas in which we weigh the potential for good and the lack of harm. It is constantly our concern that the harm done must be very little and that the benefit must be very great when you weigh these things.

1410

**Mrs Sullivan:** Just for the record, Mr Chair: I gave Mr Fram the wrong title. I know he would not want that to remain in the record.

**Mr Fram:** I was honoured.

**Mr J. Wilson:** Thank you very much for taking the time to appear today, Dr Borwein. You have made the point very clear that we need to address section 15, dealing with research. If I may say, and not to patronize you, but you have made it as clear as Dr Lowy and some of the other distinguished company you mentioned.

I made the point, on behalf of my party at the time when Dr Lowy appeared before the committee, that we would be introducing an amendment to this section dealing with research, because we agree with your comments, if the government does not clear that up with its set of amendments. We hear rumours that they are coming forward at any time.

I would reiterate to the government members, and to the parliamentary assistants if they are listening, that if you bring your amendments forward sooner rather than later we would not have to keep repeating these arguments and distinguished people like our present witness would not have to take time out of their busy schedules to keep hammering home the point. I want to make that point.

I just noticed in your brief, having gone through it, that you did an excellent job of making the point on research. But it kind of sticks out, the clipping you provided, "Patient Rights Have Eroded Ability to Treat." I know it is not something you wanted to really deal with, because I understand you want to make the point about research, which you have done, but do you have any comments on that? It is a very interesting article.

**Dr Borwein:** Yes, I do. I do believe patients have extraordinary rights. I think people have the right to be well informed before they consent to any treatment.

I labour a great deal under what the extent is of informed consent. How informed is informed consent? I talk to you about this as one who has to sit on these boards. I have to evaluate the letters of information that go out to the patients. There is no limit to the extent of the information you can give for informed consent. We could tell every patient that one out of a million persons succumbs to this particular thing and one out of a million succumbs to that. That would clearly be pointless because the chances are very small. Nevertheless, where do you draw the line between what is a small chance and what are the usual complications?

We do always bring the element of judgement to bear on that business, but I do not think anybody should be in a position of having treatment to which he or she has not consented. There must be reasonable declaration of the treatment, the pros and cons of the treatment, the alternative treatments and the consequences of not having treatment. But we are dealing here particularly, I imagine, with people who cannot themselves give consent to treatment.

**Mr J. Wilson:** Yes.

**Dr Borwein:** There again, from my personal role simply as a citizen of the province, somebody who has had to deal with relatives who are mentally retarded, my mother who had Alzheimer's, people who cannot give consent, I think certain kinds of illnesses and disabilities are extremely cruel to the person who suffers them. They also can be extremely destructive to the people who have to work with them. I think there is a place for trusting, were it is reasonable to do that, the members of a family to give consent to treatment when the person is not of a mind to be able to make those decisions. Otherwise we have large numbers of people who are free to suffer. We donate to

them the freedom to suffer if we do not take some other steps.

**Mr J. Wilson:** That is an excellent point, because we had brought to our attention just before lunchtime by a doctor from Penetanguishine the case of Gallagher, I guess it was, where the courts continued to rule in favour of a schizophrenic patient who continually refuses to accept any treatment whatsoever. The consequence is that this person is indefinitely incarcerated, perhaps because of his inability to understand that if he does not get treatment he is never going to get out and he is never going to get better.

At some point in the system—because the way the system is now it appears the courts rule in favour of patient rights absolutely. Should there be an override and who should take that decision, the care giver designated previously by the patient?

**Dr Borwein:** I think it is very difficult to designate a care giver previously because, unfortunately, schizophrenia often hits wonderful young people when they are about 18 or 20 years old. There is no way at 12 they are going to say, "Should I develop schizophrenia, I want my mother to take decisions for me." That is an impossible scenario.

I think, in the absence of any evidence to the contrary, we have to trust the families. There may well be places where you would not, and you might have good reasons for doing that, and I am sure we have the wit to deal with it. But by and large, I can only repeat what I think Churchill said of democracy, "It is not a very good system but the very best we have." We do not know anything that works better than a family, for all its shortcomings and deficits. I think it is tragic to downgrade the status, the position and the importance of family in any way. I would like to see that promoted, bearing in mind there are exceptions that will need special attention.

**Mr J. Wilson:** On behalf of my colleagues and myself, thank you very much.

**Mr Wessinger:** Thank you, Dr Borwein. I would just like some clarification with respect to your position concerning treatment. First of all, you indicated very clearly that you thought there should be informed consent. However, at the same time you indicate there should be permitted research with respect to incapable people and children. Is that correct?

**Dr Borwein:** Yes.

**Mr Wessinger:** So in effect it is only informed consent with respect to the capable people.

**Dr Borwein:** I think we are saying that if you do not allow any research on people who cannot themselves give consent, you are discriminating against them and you are permitting them to suffer in ways that you would not allow people who can give consent to suffer. So what we are saying is, yes, you have an exceptional circumstance there and because we are human beings and we can bring judgement to bear—we may not always be right but we try to be right—I think it is necessary under very stringent conditions to allow surrogate consent. You allow that all the time, for example, when you take your child to the doctor. Your child does not consent to treatment. You consent on behalf of your child to treatment.

There is an analogous position in research except that we would be much more stringent. Our guidelines say, for example, that no matter what the parent says, if the child demurs you may not do research on the child. That is not always the case with medical treatment.

**Mr Wessenger:** Just to follow that up, do you accept that you can work within the existing common law with respect to the matter of the restrictions on research?

**Dr Borwein:** We have been working up to now under the common law and under special international guidelines and official guidelines that have been established by semi-statutory bodies like the Medical Research Council of Canada, the National Council of Bioethics and so on, yes. We think what has helped us a great deal in not having it under specific legislation is that we have evolved into a better and better system. We have learned from experience where to be more stringent, where to be more flexible. We have learned from others' experience how to improve it. We are busy rewriting our whole protocol form precisely on the basis of that, very much quicker than if you have to go through a whole legal process to do that.

**Mr Wessenger:** Of course, you may be aware that statements—I understand you have read some of the comments that have been put on the record that this legislation is not intended in any way to affect the common law position with respect to research.

**Dr Borwein:** But we are troubled that it is there, and what we have seen from experience is that the interpretation accorded by you personally or people here is one thing. It is quite another thing when it is written down in law and churns into the law courts and is subject to all kinds of interpretations. That concerns us deeply, and I guess that is why we are asking because I have a sense that it is not the government's intent to suppress research in this province. So we are asking that that be removed so there can be no debate about it.

**Mr Wessenger:** Just one further comment. Is it fair to say that only therapeutic research is done on incapable people and children?

1420

**Dr Borwein:** What do you understand by therapeutic research?

**Mr Wessenger:** Therapeutic research is when you look at the risk/benefit with respect to the patient and there is a balance in favour of the benefit over the risk.

**Dr Borwein:** We would not use the term in that sense. We always look at the risk/benefit no matter what it is. The risk/benefit has to be such that the benefit is great either for that constituency of persons or for that person and the risk very small. That is an overriding consideration in all research. It does not pertain particularly to therapeutic research.

We understand therapeutic research as being something different than, for example, prevention. In other words, in regard to a treatment as opposed to let's say a prevention, a vaccine would be different from a drug which you are using to alleviate a particular condition.

**Mr Wessenger:** We have been told by Professor Dickens that under the common law therapeutic research is permitted on incapable persons, but non-therapeutic research is not permitted.

**Dr Borwein:** I bow to Dr Dickens's great authority in this field but I think that we should have it broader than that. How would you want to prevent, for example, the development of a vaccine that could protect people from schizophrenia? That would not be a therapeutic intervention, that would be a preventive measure.

**Mr Wessenger:** I assume that you will be making representations to the Weisstub committee?

**Dr Borwein:** I would be glad to.

**The Chair:** On behalf of this committee, I would like to thank you for taking the time out this afternoon to come and give us your presentation.

**Dr Borwein:** And I would like to thank you for the opportunity to do it.

#### CHEDOKE-McMASTER HOSPITALS

**The Chair:** I would like to call forward our next presenter from the Chedoke-McMaster Hospitals. As you know, you will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow us some time for questions and comments from each of the caucuses. As soon as you are comfortable, please identify yourself for the record and then proceed.

**Ms Hamilton Wilson:** It is pleasure to be here. My name is Jane Hamilton Wilson and I am the family educator on the psychotic disorders team at McMaster medical centre, Chedoke-McMaster Hospitals. I am a nurse with more than 16 years' experience working directly with individuals with schizophrenia and members of their families. I am also a very new member of the professional advisory board of the Ontario Friends of Schizophrenics.

This is my colleague, Heather Hobbs, a nurse, also with many years' experience working directly with individuals with schizophrenia and current coordinator of this multidisciplinary team at Chedoke-McMaster Hospitals.

The work of both of us, on the psychotic disorders team, is a hospital-based outpatient service, specializing in the assessment and treatment of persons with psychotic disorders. A large number of our clients have schizophrenia and continue to live at home with their families. Members of our team work in active partnership with clients and their families. Families are considered an essential member of the treatment team.

On behalf of all members of the combined clinical and research team, the names of which are on the front of our brief, we are here today to voice our concerns about the proposed legislation, Bills 74, 108, 109 and 110.

I should mention that I do not intend to read the entire brief. I will be speaking for just a short time this afternoon, hoping to summarize the points that have been made in the longer version within the brief.

Taken together, these acts will significantly change the future care and treatment of persons with schizophrenia. These changes have the potential to make it even more

difficult to respond to the urgent needs of those acutely psychotic individuals and the needs of their families.

Statistics suggest that up to 60% of the chronically mentally ill live with their families. These families are in a position of primary care givers. In the past, families were thought to cause mental illness, but we now have evidence that some families can positively affect the course and prognosis of established disease. In fact—again, lots of evidence through research—some of the best possible treatment outcomes are gleaned from the creation of a therapeutic partnership between consumers, families and professionals.

Regrettably, the proposed legislation, specifically Bill 74, fails to provide support for family-centred practice models, a model which is certainly currently in place at Chedoke-McMaster Hospitals. The voices of family members at decision-making levels have been excluded. We hear a lot of talk about a consumer-driven mental health care system. We would personally welcome such a system if, and only if, it means a system driven by the needs of all those with mental illness, needs that can best be ascertained by a full partnership of consumers, families and service providers.

I would ask you just to imagine for a moment how frightening it might be to see your own son or daughter lose touch with reality. You notice the beginning signs of psychosis and your relative gradually withdraws from the rest of the family. He or she perhaps refuses to eat, convinced that the food you have prepared is poisoned. Your relative stops taking anti-psychotic medication, believing that it too is poison. As the psychosis increases, you watch helplessly as your ill adult child prepares to leave home, too paranoid to trust even you, preferring instead a life on the streets.

You know from experience that your relative needs help, but you are powerless to do anything. This scenario is one that frequently faces our clients and their families. The stress is enormous and the burden is severe. In this situation, the ill person surely has the right and the freedom to leave home. He also has the right and the freedom to refuse medication, but on the other hand, he has a right to treatment, treatment which could restore his capacity for self-determined choices, not choices driven by a paranoid psychosis. In our opinion, mental health legislation must strike a really very thoughtful balance between the need to treat and the need to protect individual civil liberties.

That the rights and freedoms of all individuals be maintained is not at issue. We strongly support legislative efforts to empower and assist Ontario's vulnerable citizens. These humanitarian values are certainly worthy of our support. Generally, the bills proposed attempt to emphasize and enhance the dignity of the mentally ill. They also attempt to demonstrate increased awareness of their psychosocial needs. But these bills also have the potential to empower illness and increase suffering.

You see, the autonomy and real freedom of a psychotic individual lies not in preserving his civil liberties, but rather in restoring his cognitive functioning through prompt and effective psychiatric treatment. Such treatment can restore the freedom in its most central form, the liberty to perceive, to think and to make decisions free from the

distortions of psychosis. Individuals with schizophrenia are not freely choosing an alternative reality. Neither are they non-conformist or socially deviant; rather, they have a serious but in most cases very treatable brain disease.

Will the proposed legislation ensure that this young man, the man I just described, obtains needed treatment, or will the laws have us sit idly by until he becomes a danger to himself, a danger to others? At what point might this young man be considered incompetent? Unfortunately, within Bills 108, 109 and 110 a clear definition of "competence" has not been provided. Similarly, clear guidelines as to the determination of competence are lacking. The judgement of competence is a highly complex activity involving the skills and expertise of trained neuropsychiatric clinicians. The notion that advocates, presumably untrained, would assess an individual's competence to consent to treatment fails to understand the very nature of the disease or disability. The proposed legislation does not guarantee that the advocate will have the expertise to distinguish between competence and psychosis, nor is there any mention that advocates will be governed by a specified code of ethics.

#### 1430

While historically there has been good reason to doubt the efficacy of psychiatric treatments, there are now much more beneficial treatments available. Proposed changes offer a very complicated array of procedures protecting the rights of individuals to refuse such treatments, but the rights of psychotic individuals are restricted by illness and enhanced by treatment. It is not clear that these bills will protect the rights of the chronically ill to treatment.

Several of our consumers have voiced their concerns about this potential. In the words of one consumer: "When I become psychotic I want to be treated. I want to be hospitalized. I want someone to drag me to the hospital—my family, the police; it does not matter—because when I am well I'm a productive member of the community and when I'm psychotic I'm not myself and I don't make sense."

While most of us have no difficulty in making informed and rational decisions, for those with chronic schizophrenia self-determination is not always possible. The intelligent and articulate consumer I have just mentioned becomes very delusional when ill. He believes his family and the treatment team are plotting against him. His suspicions eventually lead to physical aggression and only then can he be admitted to hospital. For this young man untreated illness impairs his autonomy. It also impairs his independence. We fear the proposed legislation may unwittingly promote the tyranny of illness over his fundamental rights.

Taken together, the Substitute Decisions Act and the Consent to Treatment Act set restrictions on psychiatric hospitalization. Bill 108 appears to indicate that an individual, while capable, can grant authority to an attorney for personal care to consent to psychiatric hospitalization even if the individual later objects. But if I read Bill 109 correctly, I believe it states that only a court-appointed guardian of the person, not in fact an attorney for personal care, can give consent for psychiatric admission. Ultimately, only the court can authorize psychiatric hospitalization.

When it comes to psychiatric hospitalization, these laws appear to give greater weight to incompetent refusal than to prior competent consent. Only if a person satisfies the criteria for involuntary admission would hospitalization be expedited. Tightening consent laws but leaving committal laws untouched implies that the need for treatment will not necessarily ensure access to hospital, yet in the absence of comprehensive, community-based treatment facilities hospitals are currently the only place where treatment for an acute psychotic episode can be reliably monitored.

In 1988 the Graham report was published, *Building Support for People: A Plan for Mental Health in Ontario*. This report described a plan to develop a community-focused and integrated mental health care system allowing for mentally ill individuals to remain in the community as much as possible. The report clearly stated that the needs of individuals at highest risk for hospitalization would be given priority.

In 1992 we have before us a collection of proposed health laws and policies that will have a significant impact on the lives of these high-risk individuals. Unfortunately, in the absence of community mental health legislation, the implications of Bills 74, 108, 109 and 110 cannot be fully understood. Evidently the government has reversed the logical order of events. Unveiling community mental health legislation would enable the citizens of Ontario to place the currently proposed laws in proper context. We would urge the government to delay the passage of these bills until the vision of the Graham report is firmly in place.

**Mrs Sullivan:** I am interested in the emphasis that you place in your brief on the question of best interests versus the autonomy questions. I think the range you have spoken about in terms of vulnerable people and people who may need advocacy services, by example, is a very interesting way of analysing these bills. You have looked at people who are vulnerable, whether from physical disabilities or developmental difficulties or delayed development, people suffering from trauma and injury, people who have illness and disease, and various stages of reaction and response to determining their own self-interest in health care. I think that is a very interesting approach and I find it interesting that in a treatment centre this is recognized as being a clear determinant and basis of analysis.

As you have come to that conclusion, can you tell me, given your analysis of the different patient profiles, where you would see the advocate fit in and how the advocate could affect patients who are at the heavy end of the disease spectrum versus those who have a living—what did you call it?

**Ms Hamilton Wilson:** A problem in living. I would think that individuals who have difficulties with problems in living, an unemployed and depressed young man, for example, would rarely if ever need the services of an advocate. I would welcome the services and active involvement of an advocate in any of the current treatment that I personally am involved in, and again I must specifically point out that I work most exclusively with individuals with a

chronic form of illness. The severity ranges, of course, but we are talking very much about individuals who are chronically neuropsychiatrically ill. For those individuals, I see the role of advocates as being adjunctive and certainly providing the level of safeguard that I have heard throughout today the members of this committee are interested in.

I would worry, however, that the role of advocates is not well defined, nor is there a level of education qualification or whatever. Furthermore, there is no specified code of ethics. So it seems peculiar to me that we have many mental health professionals operating within the constraints and guidelines of a code of ethics, and then we potentially put these new people in, advocates, without that same safeguard. That certainly is a concern and a worry. But I see that role as valuable, particularly in the 10 provincial psychiatric hospitals. The psychiatric advocate role is certainly one that has been established over the years and one I believe is working at this point at a much better level than it ever did historically.

**Mrs Sullivan:** Are the social workers and chaplains at Chedoke now used to provide advocacy services?

**Ms Hamilton Wilson:** Yes, they are. I would say that the largest number of professionals involved in advocacy services are actually nurses, and that they are there 24 hours a day and are very much available on weekends and the rest.

In the psychotic disorders team at McMaster, I function within the role of family educator and work very closely with the nurses in attempting advocacy not only for the family but also for the client, in making sure that within that partnership both sides of the coin are represented and that we make sure we are not listening to psychotic wishes. We try very hard to find the best possible approach with minimal harm. Our interest is in benefit, and we have had a good deal of success in that.

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**Mr J. Wilson:** Thank you for your presentation. I think your presentation now and Dr Cleghorn's earlier today really brought a breath of fresh air to our hearings, at least as they proceeded the last week we sat and yesterday and today, because you do raise some very good points.

One of them I want to touch on, and tell you that I very much agree with, is under your section on restrictions on hospitalization. There does seem to be a conflict between Bill 108 and Bill 109. I think you are dead right or you are absolutely right when you say that only the court can authorize psychiatric hospitalization in the long run.

I am just wondering how many of your patients would take advantage of that, ie, being able to direct in the powers of attorney for personal care that hospitalization committal or hospitalization also be a part of that direction. Do you think a number of people would be able to use that tool and therefore avoid full guardianship?

**Ms Hamilton Wilson:** It would be very difficult for me to comment on adequate estimates. I would guess that a goodly number of the individuals—we work with about 65 individuals and their families—would take advantage of that option. I personally feel that particular option must be set in an appropriate context. The goal of our team is

very much to keep people out of hospital. To predict that another acute episode could happen—at the point when a person is having his first psychotic episode, when that becomes resolved we are then in a bargaining position to talk about the possibility of it happening again.

I think, when we look at that in terms of a partnership, it becomes a lot easier to talk about how we will manage your next episode as a group—your family, yourself and ourselves as a team—should it happen: what you would like us to do and to have that agreement. I can certainly see in the clients we are currently working with—again in the context of a partnership where I have no more power than the family or the individual with the illness—that we are talking about a very egalitarian relationship. In that context I think that provision would be excellent and I look forward to it.

**Mr J. Wilson:** The statistics certainly back up your team's efforts to keep people out of hospital. I mean, you do your work with fewer beds than many other facilities and you should be commended for your approach. This is something we are seriously considering; in fact we have met a couple of times on it with my caucus colleagues, and if the government does not address it we will be bringing it forward.

**Ms Hamilton Wilson:** I think there is a reason why we keep people out of hospital and that is because we have wonderful families who are care givers and who are prepared to live with individuals who I know are horribly destructive and disruptive in the home. But they hang in. They certainly have the welfare of their relatives in mind and that care giver role is quite undervalued, I believe. I would hate to see legislation undermine the very important role that families are currently performing.

**Mr Malkowski:** Thank you for your excellent presentation. This morning Dr Cleghorn and some of the professional mental health people presented. There is a bit of a controversy between those living with schizophrenia and some of the people who are trying to provide help to those people. It is interesting that some of the psychiatric staff who have talked to us have witnessed that some of the psychiatric patients have been abused when it comes to consent to treatment or when people are misdiagnosed or mislabelled schizophrenic. Myself, I have heard some psychiatric survivors, for example, who have spoken to us, who were mislabelled and misdiagnosed and who have been forced to take treatment. It really impacts and the effects of that are quite serious.

You were saying in your presentation that it is important for us to recognize the right to treatment. I would like to know where the accountability is then and how you account for the balance of the people who are misdiagnosed or mislabelled. We have seen those stories confirmed at this committee when it comes to consent to treatment. How do you find that healthy balance in terms of accountability for those who do suffer from this illness and then those who are mislabelled? How would you find that balance?

**Ms Hamilton Wilson:** Hopefully, the experiences of that are going to be decreased in future. I cannot sit here

and say that psychiatry in and of itself has not been to blame for many, frankly, horror stories that I have heard about. I do not hear about them as often now, but certainly 16 years ago, yes, there were difficulties in diagnosis and I believe that led to people being detained in psychiatric hospitals, potentially mislabelled.

I would hope that professional accountability, as nurses, as physicians, as social workers, in and of itself would prevent further such episodes.

I would also like to comment that I believe those experiences certainly have happened, but I am not certain as an individual or as a professional among this group that those individuals adequately reflect and are representative of the very large number of consumers within our province who have had good experience, who welcome treatment, and would get treatment again should that need arise.

**Mr Malkowski:** Okay, so would you agree then that it is important to provide complete information to the patient, both the pros and the cons, in terms of the treatment? Would you agree with that?

**Ms Hamilton Wilson:** Absolutely, absolutely, in that—

**Mr Malkowski:** Thank you.

**Ms Carter:** First of all, I think it is time we put behind us this argument over the causes of schizophrenia. I do not feel there is any need to blame anybody. I think we can agree that a lot of research still needs to be done on that and there are probably many causes. Also, obviously, a lot of families do a superhuman job in caring for sufferers, and I think nobody wants to belittle that.

Having said that, Bill 74, the advocacy bill, is aimed at strengthening vulnerable persons who do not have the family, friends or professional help they need or who are actually being abused. That is why the appointments advisory committee, which is provided for in sections 13 to 15 of the bill, is to be made up of consumers of the various categories and, of course, they will in turn exercise discretion as to who is to be on the Advocacy Commission itself.

Now, the question I would like to put to you is, there could be advisory committees to this commission which could have family and professional representatives on them, and I was just wondering if you have any ideas on that. For example, could they be central or regional? Should there be separate committees for professional and family advice or should they be mixed, and so on?

**Ms Hamilton Wilson:** I certainly believe there should be those committees. I would like to think they would be mixed actually. Again, in a spirit of partnership in assisting vulnerable individuals in Ontario, I strongly support the need for mixed kinds of groups where consumers are interacting with professionals and family members. Certainly I would like to see that on a regional basis.

I think the needs in northern Ontario are very different than what we have in Hamilton. We have a good spirit of volunteerism in Hamilton and a lot of committed professionals who go above and beyond in terms of committee work to make the situation we have there and to reduce the number of hospital admissions. Hamilton is a very cost

effective community in terms of mental health. Regional representation, I believe, would be highly preferable.

I am certainly aware as well of the rationale behind Bill 74, to represent those who perhaps do not have families. I see that as admirable. I certainly support that. I would ask committee members to consider that some of those individuals who are currently in need of state support, vulnerable individuals, may have historically had nasty experiences with the mental health care system. Perhaps the families have, to the point where they have now disowned those particular people. Again, I think there is more answer in working in partnership to maintain those pieces of one's natural social network so that in future the intensity of advocacy programs can be reduced, not increased.

**Ms Hobbs:** I would just like to support that. I think this kind of cooperation is happening at the grass-roots level. It is happening in the district health councils, it is happening with advisory boards to various programs in our city for sure and in other jurisdictions, I know, and I think it should be reflected in the Advocacy Act.

**Ms Carter:** I think the last thing we would want to do is to disrupt that. We certainly want to keep existing structures.

**The Chair:** Ms Wilson and Ms Hobbs, on behalf of this committee, I would like to thank you for taking the time out today and giving us your presentation.

1450

#### ONTARIO HEAD INJURY ASSOCIATION

**The Chair:** I would like to call our next presenters from the Ontario Head Injury Association. You will be given a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. Please identify yourself for the record and then proceed.

**Mr Roberts:** Thank you. My name is Bill Roberts. I am the senior manager of policy and development at the Ontario Head Injury Association. Thank you, Mr Chair and members of the committee, for inviting us to speak on behalf of the Ontario Head Injury Association and our members who include some of the most vulnerable people in our province. We are encouraged by the proposed legislation contained in these several proposed bills, and support the notion of empowering vulnerable persons and promoting respect for their rights, freedoms, autonomy and dignity.

Ontario Head Injury Association was cofounded six years ago by two parents of young persons who had sustained brain injuries. This association grew from the recognition that as a group, persons with acquired brain injury were not perceived as an assembly of people with brain injury as the underlying cause of a great variety of cognitive, physical and emotional impairments. Although we now have 28 affiliated community associations and support groups, brain injury remains a misunderstood or poorly understood problem by providers in health and social services in the broader human service network.

We acknowledge the need for an advocacy system which is non-aligned with the facility or program that is providing services to the vulnerable person as outlined in Bill 74. We are particularly interested in clause 7(c), which describes the commission's role to "provide advocacy services to help vulnerable persons to bring about structural changes at the political, legal, social, economic and institutional levels."

Within Ontario at this moment there are individuals who are not receiving appropriate rehabilitation opportunities, not just because of insufficient places or spaces in programs, but also because they have been placed in facilities which do not recognize or understand the implications of acquired brain injury. These settings include hospitals, nursing homes, psychiatric facilities and correctional facilities.

We believe there will be a considerable workload for the newly hired advocates to this commission in order to address these injustices for persons with brain injuries.

Clause 36(b) of Bill 74 describes the commission's ability to make regulations to "establish minimum qualifications and educational standards for advocates." We strongly recommend that any advocate who works with people who have acquired brain injury should be hired with a background in the neurosciences, attend university-related courses or receive orientation and training from a leading acquired brain injury rehabilitation program as a prerequisite to working with this group. While we do not expect this person to supplant the role of a neuropsychologist or attending physician, we observe that many persons who are providing care to our most vulnerable members have no training in this area, and through ignorance are creating counterproductive environments for recovery and rehabilitation.

The issue of capability is embedded in both Bill 108 and Bill 109. We wish to bring to the attention of this committee that following brain injury, individuals may make continued recovery for long periods of time. We caution this committee to ensure that not only should a vulnerable person be allowed to reassert his or her rights to self-manage, but also there is a process to review and encourage the vulnerable person, especially the recovering individual, to take an active role when possible.

In subsection 6(3) of Bill 109, "A person may be incapable with respect to treatment at one time and capable at another." Further, in section 10(1): "When a health practitioner finds that a person who is 16 years of age or more is incapable with respect to a treatment, the health practitioner shall, (a) advise the person of the finding, unless the person is unconscious."

We recommend that any treatment of non-emergency nature administered to any person apparently conscious or not, begin with information as to what treatment is about to occur. The reason for this request is as follows: (1) the possibility that the individual may be able to process this information at some level, even if he or she cannot acknowledge physically that she or he understands; (2) the increased likelihood that medical staff will respect the basic dignity of the patient in a coma-like state and not comment on that individual in a degrading manner; (3) Recent

research by Dr Roger Wood that suggests that patients in a coma-like state may improve when sensory input is regulated and patients receive orienting information from all staff involved in their care; (4) we still have no standardized definition of coma. What is coma to one person may be an advanced state of awareness to another person.

In the definitions, subsection 1(1) of Bill 109, "treatment" is defined as "anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose, and includes a course of treatment." We note that many of these treatments occur in teaching hospitals and involve research. While we see great value in continuing research and in educating students, we recommend that informed consent include respecting the wishes of patients to privacy in facilities of this nature.

In summary, we see this legislation as long overdue for vulnerable persons and we generally support the principles and processes as outlined in the proposed legislation. We have noted some reservations about the implementation of these bills and recommended methods to improve the rights and dignity of persons with acquired brain injury.

**The Acting Chair (Mr B. Ward):** Thank you very much for your presentation. We have time for a couple of questions from each party.

**Mr Sterling:** How many people does your organization represent?

**Mr Roberts:** There are currently in Ontario, through our best guesstimate, 19,000 people with acquired brain injury. We have over 5,000 people on our database of members and in other local associations, so we represent a significant number of those people who are defined as brain injured.

**Mr Sterling:** In Bill 74, the control over the advocates remains a worry of mine. There may be situations where they are not properly trained, or they get off on an ideological bent rather than being concerned or advocating, or they start making decisions rather than advocating—and there is nothing in Bill 74 which indicates that an advocate cannot make a decision; I want to make that perfectly clear. Do you think that there should be some complaints mechanism, some kind of mechanism whereby you can go to a fairly independent tribunal or quasi-tribunal or board or whatever for your people to complain about the treatment they may have been dealt by an advocate?

**Mr Roberts:** Yes. As I pointed out, through ignorance facilities sometimes really do not understand the nature of brain injury and come to improper conclusions either through misdiagnosis or non-diagnosis of a problem. Similarly, families, despite the fact that they are the primary source of support and concern and nurturing for individuals with brain injury, occasionally are counterproductive and really do not understand the implication of brain injury. That is why we support the notion of an advocate being a third party to support the rights of the individual in this process.

Clearly, where an advocate would interfere with the natural process of dialogue between a service provider and a family and go off on a tangent that is counterproductive to that healthy process, that should be brought to the atten-

tion of someone, whether a tribunal or someone within the system. So there needs to be another sort of counterbalance to the system. But that is why we support the general notion of an advocacy system, because we see this paradoxical situation where, on the one hand, you have families providing all these wonderful things in some circumstances, but in other circumstances very truly not understanding the nature of the injury and being very counterproductive and blaming the victim.

**Mr Sterling:** They are talking about 150 advocates for this province's 330 nursing homes, close to 300 hospitals and 500 rest homes. If your group was given the access to some advocacy services, where would you deem them most relevant?

**Mr Roberts:** I think we would probably see the most relevant activity taking place in institutions at this point—what we describe as warehousing people with traumatic brain injury. That is to say, institutions that do not provide any level of basic rehabilitation. Those would include general hospitals, nursing homes, and so forth.

I think there is a growing recognition among psychiatric facilities that there are patients who may have dual diagnosis that they may not be adequately equipped to treat, which is a whole other kind of issue, because they are still receiving some kind of basic treatment, although from our perspective it is not necessarily the right format.

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**Ms Carter:** In respect of advocacy, the task of an advocate as foreseen in Bill 74 is merely to ascertain the wishes of a vulnerable person, so I find it hard to see how they could do anything that was too damaging. Of course, systemic work, where they tried to alter the setup, would come as a result of dealing with many cases where they discovered problems in common, so I think that would evolve in a natural kind of way.

Also the Advocacy Commission itself has been left, I think, by this bill to set up itself the details of how advocates would be trained, so I am not sure that the issue you raise is addressable in terms of the act.

**Mr Sterling:** Could I ask one more question if there are no other questions?

**The Chair:** Yes, Mr Sterling.

**Mr Sterling:** Do you see the advocates as a friend of your clients?

**Mr Roberts:** On behalf of the individuals who have sustained the brain injury, of course, I see that as their basic role, to protect their rights.

**Mr Sterling:** But you see, those people who are supporting the Advocacy Act—and I can see a role for an advocate, but I am just concerned about the understanding of what these people are going to do when they get out there, so that people are not disappointed.

I understand the role of the advocate to be at a second level of advocacy. In other words, these people are not going to be going around in the institutions asking your people, "Are there any problems?" They are going to be there, as I understand it, if there are some significant problems and somebody is going to point one of your people

towards these advocates. Is that your understanding of this or do you think they are going to have the kind of resources to be contacting your people?

**Mr Roberts:** I would hope there would be, first of all, a considerable broadcasting of what the program is so that the general population would become aware of it, and clearly not only family members but other individuals who know of people with traumatic brain injury. Once they found out there was potential advocacy service for that individual, I think the uptake on the service would be quite high, from our perspective, because we have a 1-800 helpline that links people to services. But in the course of that it becomes evident through that helpline and our dialogue with families that often they are totally dissatisfied, but there is no alternative for them other than an institutional setting because they are incapable of supporting that person in their own home with the current level of support they are receiving.

So, again, in terms of systemic change, I think there is a role for the advocate in that and of course it would come on a case-by-case basis. You know, we already have quite a few cases that we have become aware of where we could use an advocate right now to facilitate the process of helping to identify that a person needs to be in a rehabilitation setting, for instance, rather than in a general chronic care wing of a hospital where he is getting virtually no rehabilitation.

**The Chair:** Mr Roberts and Ms Twerdohlib, on behalf of this committee, I would like to thank you for taking the time out today and giving us your presentation. Thank you very much.

#### ONTARIO LONG TERM RESIDENTIAL CARE ASSOCIATION

**The Chair:** I would like to call our next presenters from the Ontario Long Term Residential Care Association. You will be given a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow questions and comments from each of the caucuses. Please identify yourself for the record and then proceed.

**Ms Wolman:** Thank you for giving us an opportunity to present before the committee today. My name is Harriet Wolman. I am the chairman of the public affairs committee of the Ontario Long Term Residential Care Association. I was here yesterday as part of the ad hoc group that presented to you in the morning, all health care providers, but today we are going to represent our own particular interest and our own association.

With me is Mr Rick Winchell, the executive director of the Ontario Long Term Residential Care Association. He will lead off with some facts about the association. Just before we start our formal presentation, may I say to you that we do support the need for, the principles and the intent of the legislation in so far as we believe there needs to be protection for vulnerable adults and others in the community. However, we do believe that there are serious flaws in the legislation and we feel that they are of such a nature that the legislation should be withdrawn and that

there should be further consultation. We are going to make some of those points to you this afternoon.

**Mr Winchell:** Our association represents the rest and retirement home sector, which includes about 500 independent facilities. Just to clarify what we do, we provide 24-hour personal care by about 13,000 professional staff, from activation, nurses' aides etc. We provide assistance with bathing, eating, dressing, medication, community outreach activities and pastoral services. We provide house-keeping and laundry and transportation to and from medical appointments, social activities and what have you.

We basically fit in the long-term care continuum and we fill the gap between home care, those services provided in-home, and extended care, which is what the nursing homes and homes for the aged do. We provide personal daily support up to a maximum of about 1.5 hours of nursing care per day.

Our association has about 45% to 50% representation of the rest home sector in Ontario. I think it is important to preface our presentation today by saying we have long been pushing for this type of process, a complaints process on a provincial basis. We instituted a code of ethics and a commitment to residents several years ago and have, since the inception of the senior citizens' affairs portfolio, worked very closely with the Office for Seniors' Issues, formerly the Office for Senior Citizens' Affairs, in resolving family concerns and complaints and in providing an information service for the public at large when it comes to issues related to retirement living. That is the background.

**Ms Wolman:** In addition to my role as a volunteer with the association, when I am not appearing before your committee I manage a retirement home in East York, so I am a front-line worker and I understand many of the problems that we feel people in our sector will experience if this legislation is implemented the way it is.

We believe it will create great confusion for both the consumer of health care and the provider of health care. Because the legislation is so complicated, it is inevitable that there will be different interpretations of how to deal with it. Some of those points were made by the ad hoc group yesterday. It will put far too much emphasis on the individual's right to advocacy and too little on the individual's right to timely access to health care services and to care. We believe it will inhibit us in providing the care that we normally provide on a day-to-day basis.

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I would like to give you some examples based on my experience so you can understand some of the things we think we will be up against. Assuming that the legislation was passed and that a substitute decision-maker was empowered by one of our residents so that we had the authority to provide the kind of care that we might have to give him, like changing a dressing or giving medication, that sort of thing, which is something we do in the normal operation of rest and retirement homes, if we had a resident then who said, "I'm not going to take my pills today" or "Don't change the dressing on my leg"—that example of a dressing was used yesterday in reference to hospitals but it could easily happen in a private, congregate retirement

home—we would then have to take a look at that resident and say, this resident may have changed his or her mind about the substitute decision-maker, and we would then be obligated to not treat and to call in an advocate, if the advocate were not already coming in to see us. We feel it really could inhibit us with the timely application of the care we normally provide on a day-to-day basis.

I feel that the complexities of it, as illuminated by the legislation being proposed, would really hamper people who are not as vulnerable as some of the people coming in who have been described by others. They are all being lumped together, and that is something we hope the committee will take into consideration when it is looking at possible amendments.

We are also concerned about the standards in training which would be applied to the advocates who will come in and investigate situations as they arise. We understand from what we have read of the legislation that the advocate is a rights adviser, could be an information broker and could be a facilitator of problem resolution. But the role should be clearly defined in Bill 74, recognizing the situations in which an advocate may be called upon with the other two bills. We do not feel it has really been clearly expressed in terms of what the role of the advocate is and how that could actually be carried out. We think that is an important thing for us to be aware of before the passing of the bills.

We also feel that we have to create realistic expectations. Primarily, I think for the most part you will see that we represent people who will fall into a grey area. It is not the unconscious person who might be abused or might have treatment removed, but it is someone who may be vulnerable but may not be vulnerable in the same sense. I think the blanket inclusion of all is really dangerous. We feel that the consumers are going to need to be educated so that we can all understand what kind of advocacy one can really expect—what is a realistic expectation of the program once it is implemented.

We also feel that the definition of “vulnerable” in the proposed legislation is too broad. It could mean many of our residents. Should this presumption prevail, all 500 of our homes would require an onsite advocate, which we think would be very costly and would be unnecessary in—I do not know what the percentage would be—certainly most cases. We have a great respect for the invaluable care and support families commit to their relatives living in our facilities. These people already rely on their family and friends to act as spokespersons for them and, if necessary, to express preferences. It is a system that is working well and we feel that if it ain't broke, don't fix it and concentrate on the areas where the needs are really very serious.

We feel that ground rules should be developed around what is reasonable to determine an advocate's right of entry. Also, the facility should be given notice of an advocate's intention to visit a vulnerable person. I am not talking about other situations but rest and retirement homes, which are really private, congregate living centres where people go voluntarily. Many of them live there and use them as bases but still come and go very independently, although we have some residents in those facilities

who really are more vulnerable than others. Our residents have come to expect their privacy to be respected and strangers not to come in and out of the buildings uninvited. There are common areas that are quite open to the public. I think the residents who would not be involved in some of these investigations or assistances would be most offended that strangers were coming into the building and looking around.

Can we afford an Advocacy Commission? At a time when the health care system is being severely tested with funding cutbacks, it is questionable whether the province can afford to fund such a commission properly. We really question the ability of the system to focus on systemic problems. I think that if there are problems that need to be addressed by advocates, we should be looking at why these problems are occurring and not so much at intervention. We feel that, by nature of the descriptions, it appears to be adversarial rather than complementary. We are concerned that we will develop an adversarial system rather than a cooperative and complementary one.

We recommend that there be a public awareness campaign to educate members of the community about the need to plan for themselves or their family members by taking steps to create a power of attorney for personal care, naming a lawyer or applying to a guardian prior to entering a health care facility.

We support the fact that there should be people out there providing resources, support, assistance and advocacy on behalf of residents, but we are not sure that it should be done in a form that becomes investigative rather than supportive.

In residential care, various therapeutic and medical treatments are carried out by nursing staff, health care aides, activation specialists and others who do not fall under the act's definition of a health practitioner, and yet these are the people who will be involved, if Bill 109 is implemented, to obtain consent and evaluate an individual's capacity to provide consent. The role and responsibilities of these care providers must be clarified by the legislation, if it is going to apply to rest and retirement homes, because of the more informal and social nature of the interaction that many of our care providers have with the residents. The act needs to explain the process of obtaining consent when this category of care provider is also involved.

We are also concerned about the definition of treatment. In Bill 109 treatment requiring consent is broadly defined, involving nursing care and, by implication, any type of personal care. Provision of care in rest and retirement homes relies on the concept of care that is personalized to the individual. Many of us are developing a program or a plan of care. We do that cooperatively with residents and so on.

Not to be too graphic about it, incontinence is not a problem that just totally incompetent people have; there are frail, elderly people who are not incompetent who have problems of incontinence. Sometimes when they are living with us, their health deteriorates and their ability to make intelligent decisions about these habits does become somewhat impaired. If we were put in a position of not being able to recommend to residents that they wear things other

than underclothes to protect themselves or that we have to change them from time to time—even though they are mobile, dressed, walking around and eat their meals in a congregate setting, they sometimes still need to have their diapers changed. We cannot be put in a position of having someone have an accident and refuse to accept our helping them to change. It is very problematic. I mean, I am sure that no one has thought that in that case we should have to go through the whole bureaucratic process. It would be very cumbersome, time-consuming and obviously costly.

The proposed legislation does not allow flexibility in the common situation and must be changed to limit the consent requirement to clearly defined nursing care procedures or to allow a blanket consent for ongoing programs. The previous point that I made really makes that example.

The other thing we are concerned about is that we feel the protection from liability is really inconsistent. There is protection for the advocates, who are named in the bill, but there is not enough protection for the health practitioner who follows the requirements of Bill 109 and may be found guilty of an offence under the Criminal Code of Canada. We maintain that the current proposal conflicts with the Criminal Code because it can prevent a health practitioner from providing timely care.

I have touched on our recommendations. I am going to turn the microphone back to Rick and he will summarize them for you.

1520

**Mr Winchell:** Just in summary, even though the government may have developed some amendments at this point, we have not been privy to them, and we feel that further consultation would be required to ensure the changes made will solve some of the concerns that not only we but many other organizations have. OLT strongly recommends that the government table the current legislation and develop a more comprehensive consultation process with all groups and individuals.

We recommend that the government develop several pilot projects. In fact, I hark back to the psychiatric system when they piloted an Ombudsman program. I was the original Ombudsman in Ontario at the Lakeshore Psychiatric Hospital in 1974. We believe this comprehensive type of legislative package should be piloted to look at far more than just the cost, but there are an awful lot of insidious things that people do not routinely think of within the policy level.

The role of an advocate should also, as has already been pointed out, be clearly defined in Bill 74, recognizing the situations in which an advocate may be called upon with the other two bills. Education programs relating to all the legislation must be put together and implemented with consumer groups, health care providers and the general public.

We believe the definition of “vulnerable” in the proposed legislation is too broad and should be much more clearly defined. Ground rules should be developed around what is reasonable to determine an advocate’s right of entry. Also, the facilities should be given notice.

Anyone moving into a facility should draw up a pre-validated will detailing individual preferences for personal care and medical intervention in times of crisis. We recommend that the government sponsor a public awareness campaign to educate the community about the need to plan for themselves or family members by taking steps to either create a power of attorney for personal care, name a lawyer, or apply to be a guardian prior to entering a health care facility.

The role and responsibilities of care providers are not very well defined, and we implore the government to take a harder look at that. The consent bill does not allow flexibility and must be changed by limiting the consent requirement to clearly defined nursing procedures or by allowing a blanket consent for ongoing programs.

**Mr Mancini:** I have one short question. I was interested in your pilot projects suggestion. How would that work and where would you think it should work?

**Mr Winchell:** Going back to some discussions we had very early on in this process, we looked at the idea of peeling the package apart and taking, for example, the advocacy portion of it, applying it to a community and testing it in all the different applications that are outlined. That was, as I said, done in the psychiatric system, although unfortunately over a period of different governments there was not enough debriefing to pass on information.

That brings up another concern I have, that there are precedents out there that go far beyond—if empowerment is truly the intention of this package, and I believe that is what the government is intending, I applaud them for that. By its definition, we are providing ways and methods for people to help themselves. My concern is that we are in fact doing it in a way that is creating such a bureaucracy, and 10 years from now, if we have more advocates down the road than we have today, from my standpoint it is a failure. We are not empowering people. It is a contradiction.

**Mrs Sullivan:** I am interested in your recommendations. I think they have been well thought out and are logical and consistent. As a result of your first two main recommendations, I am going to address my questioning not to you, but to all three parliamentary assistants. The recommendation here, as from other groups, has been that amendments should be put forward for appropriate comment. I am wondering if the parliamentary assistants will commit now to an additional consultative process once those amendments are put on the table.

**The Chair:** Does anybody want to respond?

**Mr Malkowski:** I can tell you very directly, Mrs Sullivan, that for many years, if we look back, the PC government and the Liberal government looked at that concept of advocacy and were in support of it and did consultations. We have had two weeks and this is our third week of consultation and we are still listening to people. What we are looking for is to hear the people’s concerns; that is why we are here now.

**Mrs Sullivan:** Does that mean that the Minister of Citizenship will be bringing forward no amendments to the Advocacy Act, that this bill will remain as it is now and that there will be no further consultation?

**Mr Malkowski:** What I mean is that we are listening to the presenters, and when the public hearings are finished there will be discussions to develop amendments. But we need first to listen to the presenters.

**Mrs Sullivan:** Subsequent to those amendments being developed, will there be public consultation on those amendments? Clearly there are very serious problems with these bills. Every single group, agency and intervenor before this committee has indicated that there are problems with the bills. Will there be additional public consultation when amendments are brought forward?

**Mr Winninger:** I just wanted to add to what my colleague Mr Malkowski said.

**Mr Mancini:** No and no, is that what you are adding?

**Mr Winninger:** If you do not want to hear what I have to say—I can understand the opposition may never want to hear what the government has to say, but I am confident that we will continue to listen to constructive criticisms. I do not think it is fair for Mrs Sullivan, who has been here for part of the hearings but not all of the hearings, to say—

**Mrs Sullivan:** I have read every single brief and document.

**Mr Winninger:** Will you excuse me? I listened to you. Not every group—

**Mrs Sullivan:** On a point of order, Mr Chairman: I have read every single brief and document for those events which occurred when I was not in personal attendance at this committee. There are serious errors and omissions in this document.

**Mr Winninger:** That is not a point of order.

**The Chair:** Thank you, Mrs Sullivan.

**Mr Winninger:** It is not a point of order.

**The Chair:** Mr Winninger, you should not be commenting on people's attendance.

**Mrs Sullivan:** That is right.

**Mr Winninger:** I did not think I was, even though the opposition did a number of times yesterday.

In any event, Mrs Sullivan, if she has read the briefs and if she has read Hansard, will know that a number of those deputations said that they did not want us to wait, that they have been waiting 10 years for this legislation to go forward and the last thing they wanted was further delays. Naturally we will continue to listen to constructive suggestions to make the legislation better. If this is just a tactic to delay the bills on the part of the opposition, no; but if it is a genuine desire to improve the contents, the form and substance of the legislation, certainly I—I do not speak for all of my colleagues—have no objection to the kind of informal consultation that goes on. But we have heard a very strong message from a number of deputations. They do not want to see these bills delayed. They want to see changes, but not hold them up.

**Mrs Sullivan:** On a point of order, Mr Chairman: I believe that once again my motives were impugned. The member has indicated that the opposition is not prepared to improve, or is interested in improving, these bills. We have

indicated all along that we want to see the finest and most appropriate kind of legislation put into place. This is not it.

I have asked a question; I have not received the answer. Will there be public consultation after the amendments are on the table?

**Mr Winninger:** I have given you my answer.

**Mr Mancini:** We have heard two noes.

**Mrs Sullivan:** No and no.

**Mr Wessinger:** If you want, I am just repeating what I have said on many other occasions to Mrs Sullivan's questions. Our minister has very clearly put forward her position. She has flagged certain areas where she considers we should look at amendments. It is clear that, as far as our act is concerned, there will be amendments coming forward based on the presentations made in these hearings. We are proceeding in the normal manner, which is to listen to the public through the public hearing process. After we listen to the public, then the next progress is to proceed with the next step. There is nothing unusual about that, it is the normal legislative process, and that is the way it is intended to proceed.

**Mrs Sullivan:** It may not be unusual, but in this case it is not going to be very effective.

**Mr Wessinger:** I happen to think our legislation is very good and I happen to disagree with you, Mrs Sullivan, on this.

**Mr Sterling:** I will give notice now, Mr Chairman, to move a motion at the end of the day. I did not want to take up the time of the contributors, but I am going to move a motion which I have prepared and I will pass it around. It basically takes into account what Mrs Sullivan has put forward: that we will demand or ask that there be a two-month period after the government tables its amendments for groups to have a time to consider those amendments and that we then come back in this committee and have further public hearings so that those groups can again comment on what the legislation is actually going to be. I will be moving that motion later today.

With regard to your presentation I would like to find out, of your residents, how many would be concerned with competency? Is it 10%? Is it 50%?

1530

**Mr Winchell:** I do not think we can answer that, because the legislation as it is proposed is far too nebulous, and that is one of our major concerns. The terms "frail" and "disabled" are used. It does not necessarily mean incompetent, but as it is proposed right now there is a lot of greyness. We cannot really answer that question.

**Mr Mancini:** It is everybody.

**Mr Winchell:** Exactly. Could I just add one other very important point from our standpoint? The Advocacy Act as it is proposed right now says that there will be no proceedings or damages against the commission members or advocates. I have a real concern when you are talking about empowering people, yet you exclude some people from being accountable to the system. If the care givers are going to be accountable legally, I believe the commission members and all advocates should also be held equally accountable.

**Ms Wolman:** Mr Chairman, could I add another point? I think when we talk about a pilot project, we really feel that instead of a lot of dramatic examples that everybody could give in terms of what might happen, it really makes some sense to take a particular situation, whether it is a rest and retirement home or a community, a small town—I do not know; it would have to be designed and it would have to be thought through—and see how the system would work and see whether or not these bills really have application. You have to look at it in a hospital setting, you have to look at it in a private congregate communal setting, communal living, and you also have to look at it out in the community to see whether it would work.

If a resident who has chosen or whose family has persuaded him or her, validly so, in one of these grey situations, to live in a congregate setting such as a retirement home decides that he does not want to live there any more and an advocate comes in, what does the advocate then suggest? What does the advocate do? The person may not be capable of living on his own yet may not be incompetent under the Mental Health Act and could be a frail elderly person who wishes he did not have to be given care. Will the long-term care system then be adequate enough, with the proposals the government is making, to make sure that such a person, if living in the community, would have sufficient supports out there if, for instance, he did not have children?

It is a very complicated situation, and before a huge bureaucracy is put into place and costs are driven up, it seems to me to make sense to test it out to see whether it would really work, and it has to encompass more than just one aspect of it. We are a part of it, but others are a part of it as well, and so are people who are living in the community, frail people living out there in the community independently.

**Mr Sterling:** Could I just ask one question which has come up in this submission as well? The normal day-to-day taking care of in particular elderly people, people who are not capable of taking care of themselves—nursing care, cleanliness, personal hygiene or whatever—as I read the legislation, that would be a treatment. If I am incorrect, I would like to be corrected. Is it possible, or have the ministries tried, to divide that kind of care away from the other kind of care, which I think is where most of the public is in terms of dealing with this legislation? Is it possible to do in language?

**Mr Wessinger:** Is that addressed to me, Mr Sterling?

**Mr Sterling:** Yes.

**Mr Wessinger:** I think that first of all we should clarify what this legislation does with respect to that. It does not cover personal care delivered by non-health-practitioners. For instance, in the brief it describes some of the particular types of treatment. I will give you examples of what I think would be personal care and as long as they are not delivered by a health practitioner would not be covered by this act: feeding, unless it had to be feeding by tubes; positioning a patient for comfort to prevent bedsores; changing a patient if he or she is incontinent. If those were

delivered by a non-health-care-practitioner, that would not be covered by this legislation at all.

**Mr Sterling:** I guess part of the concern, when you separate it on the basis of who is providing the care, is that you are encouraging people to have less-qualified people do things which are quasi-medical. Do you follow what I am saying? If, for instance, the decision by a retirement home is either to hire a registered nurse's assistant or someone else who does not have any professional designation, you are asking them to hire the one without the professional designation because of this legislation. Would you not be better to draw the line in terms of what is included within the treatment and what is not treatment?

**Mr Wessinger:** That is really a good point to ask the individuals concerned, if they believe that there should be a distinction between personal care and treatment as described by a health practitioner and whether they feel there should be a division. I think that is something we should ask their advice on.

**The Chair:** Very briefly, please.

**Ms Wolman:** I have some difficulty with the way you dealt with your definition of a health practitioner doing certain of these things. In a home the size of the one I manage, which is 55 residents, it is very often my nurse in charge who provides some of these services, who is a health practitioner and subject to the College of Nurses of Ontario and so on. There is no way, as a responsible manager, that I would hire a less-qualified staff person. So by virtue of the fact that I would have that person on staff and on the premises 24 hours a day, we would put ourselves under the legislation because I would not sacrifice the professionalism or the quality to be exempted from it. That would not be my goal. My goal is to deliver the best and the highest quality level of care.

**Mr Malkowski:** I am wondering if you have any specifics in terms of recommendations related to the Advocacy Act; anything specifically in terms of amendments you would like to see.

**Mr Winchell:** We certainly do. Specifically, we would like to see the advocacy portion, Bill 74, pulled out of the package and trial-tested in a community so that we can all work in partnership in looking far beyond just the legal implications and the actual delivery system itself. That is our foremost recommendation to this government.

**Ms Carter:** Your second recommendation is that the legislation be tabled and a comprehensive consultation process be embarked upon. It seems to me that this question has been under discussion for years, not just with this government coming into power. We have had the Fram commission, O'Sullivan, SARC—you name it. We are now engaged in a very comprehensive process of listening to suggestions, I would have thought. I wonder what else you feel is needed.

**Mr Winchell:** All right. I appreciate your point. I should emphasize—and one of the concerns that we have had from the outset is—that other than receiving the proposed bills and being invited to present to this particular committee, we have never sat down face to face with any

representative from government and been asked our opinion, particularly at the developmental level where we think we could have snipped a lot of the concerns in the bud.

**Ms Carter:** I have to say that I—

**Mr Winchell:** I just wanted to add to that: One of the additional concerns, and probably a further demonstration of the frustration we have around the consultation process, is that it is our understanding that there have been some amendments already drafted which have not been shared with us. It is difficult for us to appropriately input into the system if we do not share and work together in this.

**Ms Carter:** But on the other hand, and I think this has already been mentioned, we do not wish to put amendments forward until we have heard the input. Then, of course, there will be further discussion.

**Mr Winchell:** But I understand there are already some amendments out there which I think we could—

**Ms Carter:** Not in any file I saw. They are being considered. The consultation is taking place on them. The other point I wanted to make is that I think you see—

**Mr Winchell:** Mrs Carter?

**Ms Carter:** Sorry.

**Mr Winchell:** I just wanted to add, that is why I quite support the idea that once the amendments are finalized, we have a period of time to respond appropriately before this goes forward.

1540

**Ms Carter:** I see, okay. My other concern is the way you seem to envisage the Advocacy Act working, as far as your institutions and so on are concerned. It seems to me that most people, whether they are in a family or a residential home, are well looked after. This act would not apply to them in any way because they would have no need of an advocate. But can we not accept that there are some people in some situations who may fall through the cracks and not have their wishes listened to and who may need somebody to come in and listen to them?

**Mr Winchell:** Absolutely.

**Ms Carter:** I wonder why you see this as such a threat. An advocate will come with the intention of seeing only a particular person whom in some way he has heard about. All they will do is have a private conversation with that person, listen to his wishes and do their best to act upon those, and that is all.

**Mr Winchell:** I would like to respond to that. I can draw upon my own personal experience, which is four years as the first psychiatric ombudsman in this province in the early 1970s. I can tell you with all confidence that it was a very workable system. It was anything but adversarial. It was very conciliatory, complementary. We worked with patients, with family members and staff. In fact, in a lot of cases, staff were the ones who initiated the process because it was helpful to the whole therapeutic process.

However, I have to tell you that what started out as a very workable program has turned into, years later, a system whereby there are, separate from administration, separate from the entire institution, fully employed lawyers at every

psychiatric hospital in this province, and it is extremely adversarial. Staff are very concerned about carrying on their job with a lawyer looking over their shoulder 24 hours a day. That is our concern.

**Ms Carter:** Our act is specifically—

**The Chair:** Thank you, Mrs Carter.

**Mr Winchell:** We believe strongly in the intent of this proposal. We just have concern about the fact that we are not looking far enough down the road.

Interjection.

**Mr Winchell:** I would like to meet who said that.

**The Chair:** Ms Wolman, Mr Winchell, on behalf of this committee, I would like to thank you for taking the time out today and giving us your presentation.

#### HOSPITAL COUNCIL OF METROPOLITAN TORONTO

**The Chair:** I would like to call forward our next presenters from the Hospital Council of Metro Toronto. Good afternoon. Just a reminder, you will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Mr Gamble:** Thank you very much, Mr Chairman. Good afternoon, ladies and gentlemen. My name is Paul Gamble. I am the president of the Hospital Council of Metropolitan Toronto. With me this afternoon is Sharon Nettleton, the vice-president of the hospital council.

By way of background, the hospital council is a voluntary association that represents the diverse needs of the 51 hospitals here in the greater Toronto area. Our membership includes all 42 hospitals within the boundaries of Metropolitan Toronto, as well as a corporate membership with the University of Toronto. In addition, nine hospitals in the surrounding municipalities of Durham, York and Peel are also members of HCMT.

The association provides administrative and coordinative services for region 6 of the Ontario Hospital Association as well. HCMT, as an association, is actively involved in the development of policy as it affects our member hospitals, local health planning, data collection and analysis. Last fall, as part of our ongoing environmental scan of issues likely to affect our membership, our strategic issue identification and research committee reviewed Bills 74, 108 and 109. We prepared a written response dated September 24, 1991, which was submitted previously to the committee for your consideration.

In general, I think it is safe to say that HCMT supports the spirit and intent of these three bills; however, our membership did express a number of concerns with respect to specific proposals contained within, particularly with respect to certain issues on implementation.

I would like to take a few minutes now just to briefly review our position of September. After that I will ask Ms Nettleton to bring you up to date on what has occurred in the association as we have continued our discussions during the past number of months.

Beginning with Bill 74, the Advocacy Act, particularly with respect to accessing advocates, as public facilities where many vulnerable individual reside hospitals and their staff will naturally have a role to play in assisting and directing vulnerable persons to advocates. It is our belief that hospitals should participate and be represented on the committee responsible for designing the access process.

With respect to advocates and patient-client representatives, HCMT felt hospitals should participate in the development of guidelines for advocates and the existing patient-client representatives in the institutions.

As far as the assessment of vulnerability went, HCMT felt that the successful implementation of the Advocacy Act would require a clear specification of which health practitioners are responsible for making assessments regarding vulnerability. The act should stipulate who is responsible for identifying the vulnerable individuals and who possesses the ultimate authority to classify an individual as vulnerable.

We also felt that the education of advocates and staff working in facilities where vulnerable persons reside is critical to the successful implementation of the act. Hospitals should participate in the planning and education of advocates and employees.

It was also noted in the September brief that the Advocacy Act does not indicate that any recourse will be available for vulnerable adults or their next of kin who may be unsatisfied or ill served by the advocates. We therefore felt that the act should establish some mechanism, an agency or a board, to process and respond to any complaints or concerns regarding advocates which may be lodged as a result.

Concerns were raised by the membership with respect to the section on right to access of records. There may well be occasions when the time necessary for retrieving records will exceed the four days stated, particularly with respect to the retrieval of records that may be stored offsite. Facilities should be permitted an exception to that four-day rule where circumstances require and are appropriate.

Our final comments with respect to the Advocacy Act dealt with the section relating to the rights of entry. While HCMT supported the right of advocates to enter a facility to meet with vulnerable persons, we recommended that when possible advocates provide notice before entering a facility, so as to allow time for the staff to schedule meetings, prepare the facilities, rooms, whatever the case may be.

Moving on then to Bill 109, the Consent to Treatment Act, HCMT again noted a number of areas of concern.

With respect to the section dealing with the assessment and definition of capacity, HCMT felt there should be demonstrable standards or criteria upon which consistent and reliable judgements can be made regarding an individual's capacity to understand and appreciate the consequences of a particular treatment. There must also be quality assurance for these competency assessments. The assessors of competency must be trained and some certification process must exist.

The Consent to Treatment Act does not address the issue of public education. In order to ensure that the public

is fully informed about the Consent to Treatment Act and the rights of patients, HCMT felt the legislation should establish a public education program as well as an education program for health care personnel.

With respect to the section on consent on behalf of an incapable person, HCMT concluded that regulations or guidelines should clearly indicate what constitutes a reasonable inquiry into the existence of persons referred to on the consent list. This would assist the health practitioners to fully abide by the intent of the legislation.

Finally, dealing with the emergency treatment of incapable persons, HCMT supported the principle that an individual's rights regarding his or her personal care should be followed when the individual is incapable of making his or her wishes known, if those wishes have been made at a time when the individual was capable.

To facilitate this process, we recommended that the Ontario health card be coded to indicate whether an individual has a power of attorney for personal care, the name of his or her family physician and next of kin. Knowing that these wishes exist could be problematic, especially in emergency situations.

As far as Bill 109, the Substitute Decisions Act, went, HCMT supported the spirit of that proposed legislation and had no particular comments or concerns to make.

As I noted, that is a very brief summary of the position paper that was submitted last September. Now I will ask Ms Nettleton to bring you up to date on our further discussions on these matters.

1550

**Ms Nettleton:** We have taken advantage of the opportunity before us—and that had to do with the delays, I guess, of this committee in reviewing the legislation—to have further discussions both within our membership and with other organizations. I would like to present to you today some comments, some other concerns that we have had regarding mostly the implementation of the three pieces of legislation.

Some of the input has been received through the affiliate groups that are associated with the Hospital Council of Metropolitan Toronto, and these are 13 organizations that provide care within the hospitals. These associations involve social work, nursing, health records, occupational therapy and physiotherapy. They are for the most part the front-line workers within the health care system in hospitals.

Some of the concerns that have been raised—and I will briefly highlight the results of some further discussions that we have had—are as follows: First of all, we are concerned that changes may have already been made to the legislation since second reading—our concerns, I guess, follow from the Ontario Long Term Residential Care Association as well—and that consumers and other stakeholders such as ourselves may be commenting on issues that are no longer relevant. I am sure you have heard this in other forms and from other presenters.

Second, we are concerned that in the consultation paper on the redirection of long-term care, no reference is made to the proposed acts which will have significant implications in the care and delivery of long-term care services.

We would definitely like to see some overlaps, some reference made to how long-term care is going to be redirected and reformed vis-à-vis these three very important pieces of legislation.

With respect to the Advocacy Act, we are concerned that if a physician, during an assessment, determines that a patient is incompetent, under the proposed legislation the physician would be required to cease all medical procedures while an advocate is being sought; and this not only involves physicians, it involves many other health care providers. We are concerned that this could really delay treatment. It could delay assessment of treatment, any kind of health care process until an appropriate advocate or substitute decision-maker is appointed. The delay that this sort of diagnosis may cause in the administration of procedures might force health providers to ignore the patients' cognitive status and continue with treatment and assessment procedures. This is really putting the health care professional into a very serious dilemma. We think those reviewing the draft legislation and those working on the policies should take this into serious consideration.

The proposed legislation also assumes there is an adversarial relationship between patients, family members and health practitioners, and again, you have just heard it from the presenters before us.

It is also presumed in the Advocacy Act that there is a need for an advocate, and that this need is universal. I think we have to be very careful here. This is clearly not the case; not everyone requires an advocate. Clearly, the intent of the legislation is to find advocates for those who do not have them, but in the implementation it is very confusing for health practitioners and administrators to interpret the legislation before us. It might deter current and future providers—and this is what we have been hearing—from assuming the responsibility for care giving in an institution and in a home. Clearly, this is not the intent but we have to address this, and these are concerns that HCMT has heard.

The advocate as presented in the legislation is also generic in some fashion. Realistically, advocates will be required to work in a variety of social and clinical settings, and they will be required to have specialized knowledge of various procedures and medical practices. The legislation does not specify whether these advocates would be required to have specialized training, and we think this is clearly important and something that the legislation and policy should address.

In lieu of forming an Advocacy Commission, we are wondering if perhaps the Minister of Health, the standing committee and the other ministers may wish to consider the possibility of using existing resources within a ministry or within other government offices to oversee the implementation and the coordination of the legislation. We are wondering here if, for instance, the Office for Senior Citizens' Affairs and/or the Office for Disability Issues—offices that already exist and have some expertise in this area—might be involved in the implementation of the Advocacy Act. A viable option to the existence of an ongoing advisory committee might be to form time-limited, consumer-focus groups using the existing advocacy groups. The use of these groups might be more cost-effective and might

provide a broader and more timely focus to issues related to advocacy.

With respect to the Consent to Treatment Act and Substitute Decisions Act, we are looking at how they might impact on the role of patients in research, and we have concerns that the proposed act may restrict the number of individuals who would participate in clinical studies and essential research. These areas are often forgotten about but clearly, from a medical point of view, are valuable. It is very important. Medicine and other medical procedures advance based on our knowledge, our understanding and our use of individuals in research.

Ethical standards already exist to protect patients in research activities and to prevent abuse, and these standards are monitored by the institutions undertaking the research, by professional regulatory bodies, through internal and external audits and accreditation processes.

There are concerns among researchers HCMT has heard from that the implementation of the proposed legislation would diminish research dollars and world-renowned academic and research endeavours in Ontario, and we would like to bring this to your attention as well.

In summary, from recent discussions we have had with our members and discussions with other organizations, we would definitely like to see a consultation process following amendments made to the draft legislation. We think it is necessary. It would not be meant or should not be meant to stall the passing of important pieces of legislation, but it could be used to overcome problems, difficulties in implementation that would be unnecessary. We also, in summary, would like to see some rethinking around the implementation of the Advocacy Act.

**The Chair:** Thank you. Questions and comments. We have five minutes for each caucus.

**Mrs Sullivan:** I appreciate this brief and, in particular since our last exchange, your underlining of the necessity after redrafting and the putting forward of amendments for an additional consultation period. We really feel that is very important.

I note that in your September 24 initial submission you indicated you were supporting the Ontario Hospital Association analysis of these bills and that you have subsequently added to those, and I think have made some good points. Yesterday the OHA along with various other organizations including the Ontario Medical Association, the Registered Nurses' Association of Ontario and so on, came before this committee and asked that the legislation be withdrawn and substantially redrafted for public comment. I would like to know, for the record, if the Hospital Council of Metropolitan Toronto concurs with that decision.

**Ms Nettleton:** Yes, we do.

**Mrs Sullivan:** I think some of the things I find most interesting and that we may want to explore in a subsequent session are some of the proposals you have put forward in relationship to a kind of Advocacy Commission that might be workable and cost-effective. They are interesting ideas.

While Mrs Carter appears to be under the impression there had been a consultation in relationship to a model,

indeed there had been no consultation with respect to a model for advocacy services at all, nor is there any definition included in this act. The definitions for the role and work of advocates would not be done in any public forum but by regulation. I wonder if you would like to comment on the role of the advocate and how that role should be defined in a public way to make it a viable role.

**Ms Nettleton:** I think there are other ways of accomplishing the same task, and I do not think that externally we have been apprised, have been permitted the opportunity to be part of the policy that went into this legislation, from an implementation point of view. Clearly there has been a lot of discussion with a lot of individuals on the policy and the work of the Fram commission that led up to these pieces of legislation, but they are so important that the hospitals clearly want to see the legislation proceed but in a way that is going to work, that is going to benefit the individuals we are addressing this legislation to. Those are the patients, those are the consumers. Certainly the providers, in many instances, are advocates right now and do not want to be put in an adversarial position so that they are not their patients' or their consumers' advocates.

1600

**Mr J. Wilson:** I want to begin by thanking you on behalf of my colleagues. I know that over the time I have been Health critic the Hospital Council of Metropolitan Toronto has been very helpful in providing data to us, the other opposition party and the government. To be fair, you have been very accessible and very helpful in helping us to come to grips with health care issues. I find that in your brief today.

I appreciate your update of the September 24—perhaps that is not surprising to you. I did notice your comment, though, that you felt the intent of the legislation was to find advocates for those who do not have them. If that is the belief out there, then certainly, as you have correctly pointed out, that is not the way the acts read. Having seen the leaked document released by the Liberals on the government's comments on this legislation and the urgency for this legislation as a priority for this government, I frankly do not believe that is the intent of the legislation. The intent of this legislation is that it be mandatory to call in an advocate. It seems to me that it is up to the discretion of the advocate how that person will act in that situation, because we have seen that there are no controls or accountability mechanisms in the bill.

Is that just your hopeful expression, that the intent of the bill is to have advocates where they are most needed, where people do not have families? We have certainly had a lot of families, a lot of lawyers and a lot of other people say, "If that's the intent, it sure doesn't read this way."

**Ms Nettleton:** Perhaps there is a need to go back to basic principles, just to ensure that, in redrafting or reworking these three pieces of legislation, the principles are well articulated, that we know why we are proceeding with these three pieces of legislation. With respect to the Advocacy Act, I do not think it is clear. A lot of organizations, including ours, are wondering what the intent is. Going back to the Fram report and other pieces of policy and

correspondence leading up to these pieces of legislation, we assume that the original intent is there, but we are confused by what was put in front of us.

**Mr Malkowski:** Thank you for your presentation. When you were talking about a board for processing complaints, do you anticipate that this board be part of the commission, like the Law Society of Upper Canada and the College of Physicians and Surgeons of Ontario, a more internal board for processing complaints, or would you prefer it to be independent and separate? Could you clarify that, please?

**Ms Nettleton:** I do not think we have gone that far in our thinking, but there is not a form of addressing complaints in the existing legislation. That needs to be addressed.

**Ms Akande:** Thank you for the presentation and the information. I was interested in your suggestion that we perhaps use the machinery or the offices that are already in place in order to provide the kind of system that would provide care or advocacy. It was certainly the intention to provide a standalone system that would not be compromised. This is interesting to me because it is part of a discussion that had been held for a long time around the issues of advocacy with adult protective service workers who felt that their positions were seriously compromised by the way in which they worked, the groups for which they worked and the way in which their role had been set up. In light of the criticism with that example, and there are others I could give you, would you still support the machinery that is already in place for those with disabilities or seniors be used for advocacy?

**Mr Gamble:** I think the short answer is, yes, we would still support that. Part of our concern we have heard during our discussions over the last several months as this debate has continued among our members—and I think that is apparent from what we have presented this afternoon. This did not terminate last September when the brief was originally prepared, but the debates have continued and there is obviously a great deal of interest. As Sharon has already commented, there is the concern of a clarity of intent, and also a concern with the additional bureaucracy, the additional requirements being added to a system. If there is an option or an opportunity to take an existing mechanism and have it function in the appropriate manner, and it may require some adjustment to do that, we recommend it should be examined as one possibility.

**Ms Akande:** And that having been examined, could I further that just a little? That system is already in place. It is not as wide as we would have liked it to be and certainly it requires and bears improving, but you recognize that even where that system is in place and is used quite heavily in some districts and areas of this province, there still are many complaints that there are people at risk who still require advocates. You would still, in spite of that, say the system was sufficient.

**Mr Gamble:** Let me clarify my understanding from our comments in debate. It is not simply accepting the current, it would be building upon that and beginning to use a model already in place as opposed to adding an additional approach. But where there are limitations, I

think part of what needs to be examined is where those limitations are and their functional ability. If necessary, it would have to be addressed.

**Ms Akande:** I am concerned about two other things. One is that your reading of this advocacy legislation is that we have designed it in a way that the advocate is in an adversarial position, or at least so you have described it. Am I not correct? I am wondering why you infer that. It is not part of the information that I take out of the reading. I see the advocate as potentially adversarial, if required, but also supportive, helpful in many ways, not only to those in the medical profession but the families, the persons themselves. May I understand why and from what place you take the reading or infer that it is adversarial only?

**Ms Nettleton:** I think the adversarial part of it is really between the patient, family, consumer and the health provider. It really pits one against the other, not allowing the current health providers to be the advocate that they currently are.

**Ms Akande:** May I suggest that in some cases, the concern with the system is that regardless of the health provider's intent, he or she may be working (1) in opposition to the will of the patient or the client or (2) in opposition to the will of the family of the patient or the client. In that case, the way you state it, it seems to put the person in the medical profession in a prior position of greater importance. Was that your intent?

**Ms Nettleton:** No, and it clearly does not. The providers and I do not think the practitioners would see themselves in an elevated position. Clearly, they are in the professions they are in for the most part because they have a desire to help, treat, assess and do what it is they do best, and they do not want to be put into the situation where they are working against the people they are intending to help.

**Ms Akande:** And the advocate would just ensure that kind of relationship?

**Ms Nettleton:** Hopefully, if that is the way it worked. The providers whom we have spoken to find that in some situations this adversarial relationship might interfere with the way in which they would help and treat. That is their main concern.

**The Chair:** Mr Gamble, Ms Nettleton, on behalf of this committee I would like to thank you for taking the time out and coming and giving us your presentation today.

1610

#### COUNCIL ON AGING, WINDSOR-ESSEX COUNTY

**The Chair:** I would like to call forward our next presenters for the Windsor Council on Aging. Just a reminder that you will be allowed a half hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow some time for questions and comments by the caucuses. As soon as you are comfortable, please identify yourself for the record and then proceed.

**Ms Derbyshire:** I am Carol Derbyshire and I chair the advocacy committee for the Council on Aging in Windsor.

**Ms Johnson:** I am Deana Johnson. I am the executive director of the Council on Aging in Windsor.

**Ms Derbyshire:** We are here to respond only to Bill 74. We would like to congratulate the province for moving forward in the area of advocacy; for ensuring that the rights of all its citizens, particularly the vulnerable, who may be unable to speak for themselves, are protected.

We encourage a thorough, yet time-efficient community consultation process and such subsequent revision of the legislation as is seen to be appropriate following input from consumers and concerned groups. There are areas of concern and importance that we would wish to highlight.

Under subsection 6(1), while the Council on Aging applauds the commitment to delegating a majority of the appointments to consumers, a statement may be needed to clarify the variety of consumers targeted. The most vulnerable consumer may not be able or willing to function at the commission level.

Section 35 says, "An advocate who discloses...information about a vulnerable person obtained in the course of his or her duties is guilty of an offence and is liable...to a fine...." The wording in subsection 29(4) states that information may be disclosed where bodily harm to another person is a concern. It is an offence, though, to disclose information where the advocate is aware of potential threatened suicide. This places the advocate in an impossible moral and ethical dilemma. While the right to self-determination is not argued, each case must be based on its own merits, without the advocate being placed in jeopardy.

Non-instructed advocacy: Self-determination and empowerment are the most important tenets upon which advocacy is developed. However, there are cases where vulnerable adults are unable to ask for assistance or unaware of the need for assistance, for example, older adults suffering from dementias, or an older adult being financially abused and neglected by a family care giver who is also the substitute decision-maker. There must be an avenue for such individuals to access advocacy services through a third party.

Under implementation:

Subsection 6(2): The appointment of commissioners is crucial to the success of advocacy programming and they therefore must be selected with care. Commissioners should have a sincere interest in the rights of all citizens and a true understanding of the fundamental issues of self-determination. A process must be instituted whereby organizations such as the Council on Aging have a means by which to express their ideals, concerns, issues related to representation.

Under clause 7(1)(e), the Advocacy Commission is charged with the responsibility to "ensure that community development strategies are applied in the provision of advocacy services." While organizations such as the Council on Aging may not wish to be a part of the actual provision of service, they should be key players in promoting community development and liaison. The Advocacy Commission

should understand and work closely in each community, with current efforts towards social planning and development.

Section 13: Representation on the advisory committee should include input from organization such as the Council on Aging. Representation on the advisory committee will need to have regional consideration: southwestern Ontario is often overlooked, while issues are quite different from other locations.

Under sections 21 and 22, the system to back up the rights of the advocate and client must be in place at the local level, for example, right of entry without a warrant at any time.

Under clause 36(a), the criteria for the use of non-profit community programs should be carefully developed with input from the community. No one strategy or design will work successfully across the province. The designated programs must be totally perceived as having no conflict of interest or risk the likelihood of losing credibility.

Under clause 36(b) the act must be specific on the selection process for advocates. If non-professional, community-based advocates are to be utilized, there must be provision for ongoing screening, training and extensive supervision. We understand that qualifications and standards for advocates will be established. We wish to reinforce the importance of this.

Continuing community education cannot be ignored in this process. Those individuals, institutions and organizations that are most affected should be a top priority, for example, rest home operators, nursing home administrators, local judiciary, law society, police and social service personnel.

The commission has the authority to develop regulations on a wide range of advocacy issues. These regulations must be clearly specified prior to the other acts coming into force; otherwise the commission will be faced with immediate obligations that it is not prepared to meet. If proclaimed on the same day, extensive changes will occur at once. It is imperative that affected individuals, institutions and organizations be adequately prepared. Therefore, a process or system for dealing with the potential immediacy of advocacy issues must be in place prior to the proclamation.

That is our presentation.

**The Acting Chair (Mr B. Ward):** Thank you very much. We have time for a couple of questions from each party.

**Mr Mancini:** Welcome to the committee. We have heard a lot of briefs regarding advocacy and some of them, like yours, encourage the government to have further consultation once amendments are made. You have dealt strictly with Bill 74 today. What would your opinion be of a pilot project?

**Ms Johnson:** I believe that in many communities pilot projects are definitely the way to go. As we said in our brief, each community is so different. What works in one community may not work in another. We have seen that in a number of other different structures that have hit across a province, where they do not work in Windsor because they are programs set up based on one particular area's design.

Certainly piloting and easing in the projects is a way to go, and that way you can also use what is already available in a community. Many communities have services available, and some advocacy services. Learning how we can use them and build them into the structure can also be cost-effective.

**Mr Mancini:** Short of a pilot project in a limited number of communities across the province, would you in any way be concerned, after amendments were produced by the government in response to the briefs and consultation we are going through, if another period of time was taken by a legislative committee to actually hear from the public and interested parties on the amendments?

**Ms Derbyshire:** I think while we agree that we need to pilot projects, we need public consultation and we need to hear from consumers, that can be an ongoing process. Oftentimes what we see is a consultation process that begins and ends, a change occurs, we try a program for a while and then we start a new consultation process. Consultation should be ongoing. Ongoing changes can occur. Adaptations can be made.

One of the concerns we have would be to wait until it is too late and there are too many other problems that have evolved and all of a sudden we are back 10 years and we are starting over again. I do not think we want to wait another 10 years before we implement; we can start implementing slowly. It does not mean we have to have the whole package tomorrow, but we need to start looking at it.

1620

**Mr Mancini:** I kind of like what the witnesses are saying to the committee. I think what the witnesses are saying is that the accomplishments we foresee are in fact important and needed, too important to be done hastily and shabbily and too important to be thrust upon communities that are not prepared to implement them properly. I think that is what some members of the committee have been saying, and I am happy to hear that this particular delegation is saying the same things. I agree with your final comment that just because we want more consultation and appropriate implementation, it does not necessarily mean that we want a 10-year waiting period. I think what you need can be accomplished.

The other thing I have learned in Parliament is that it is not necessarily proper to speed legislation through, because even those of us who have had only 18 months' experience in the Legislature know how difficult it is to go back to reopen legislation that has been passed. Governments just do not have the time and, on some occasions, do not have the will to do so. When we are passing important legislation, I think it is important for us to be wary of that and to be wary of the fact that we must be proficient the first time around.

**Mr Sterling:** Thank you very much for coming all the way to Toronto to present this big brief. I have some concerns with regard to Bill 74 in that, although they mention a volunteer advocate, there does not seem to be any definitive line as to when a professional advocate would be utilized or called in and when a family advocate would be adequate

or when that would fulfil the purposes of the person who is incapable of making the decision. When we tie that to Bills 108 and 109—I do not know if you have had a chance to read them or not—it is not quite clear whom you call in. Do you have any concerns about how you utilize volunteer advocates in this legislation?

**Ms Johnson:** We have had many conversations related to volunteer advocates and their use, and certainly there is a role for a volunteer advocate in a continuum of advocacy service. That is why I say I believe if you are putting a program into a community you need to look at what is already available in the community. Many communities have volunteer advocates already in place. That does not preclude the need for professional advocates. If advocacy is haphazardly presented, then we can fall into more problems and more dire circumstances can occur. To have a combination of professional and volunteer advocates working together in a continuum can be a very effective tool and again very cost-efficient.

**Mr Sterling:** How many people live in the Windsor area now?

**Ms Johnson:** Approximately 200,000 in Windsor proper.

**Mr Sterling:** Under this legislation they are predicting they would have 150 advocates for the province. That would mean you would probably have three advocates for the whole city of Windsor. Do you think that would be adequate in terms of dealing with all the various institutions and the various needs that are put into Bills 108 and 109 for these people?

**Ms Johnson:** When is anything ever adequate or enough? Certainly three is more than what we have now. We have a core group of volunteer advocates in an organization in Windsor. We also have an ombudsman program that works within Windsor. Those are very effective programs. However, if we have advocacy that works only with specific groups and can only work in a specific framework and does not necessarily have legislation to fall back on for authority, then we have no clout with those people who are the most vulnerable. Three advocates with authority are a lot more power than an army of advocates with no authority. The legislation can give the power to the individuals who can then work within that continuum.

**Ms Akande:** Thank you for your presentation and for the information. The combination of volunteers to act as advocates and those who would be put in place through this legislation with, as you describe it, authority: Certainly they would operate as a continuum, or is that what you envisage?

**Ms Johnson:** Certainly.

**Ms Akande:** Yes, as a kind of reference, because one of the things we emphasize is that everyone is in fact a small-a advocate for those who are most vulnerable, so it should be assumed.

I somehow read your response to Mr Mancini's question a little differently from the way he does. What I thought you might have been saying, and please correct me if I am wrong, was that you encourage the implementa-

tion of the legislation, recognizing that ongoing consultation and refinements may be made while it is enacted. Am I more—

**Ms Johnson:** Certainly, and that is in the notes, that while we encourage consultation, it has to be time-efficient. It has been dragging for a fair amount of time.

**Ms Akande:** I just wanted to clarify.

**Mr Mancini:** A couple of months of hearings would not hurt. Go ahead.

**Ms Johnson:** You are just being honest.

Interjections.

**Ms Akande:** We have put enough words in their mouths.

**The Chair:** Are you done, Miss Akande?

**Ms Akande:** I am finished.

**The Chair:** Thank you very much. No further questions or comments? Mrs Carter.

**Ms Carter:** I have a comment and a question. You are querying the selection and training of advocates, and I think the intention there is to leave decisions about that to the actual commission when it is set up so it will in fact be arm's length from government and as free as is possible of conflict of interest as regards any government department. I think that is why that is left somewhat vague in the act.

Of course, the thing that is specified is the composition of the advisory council, in section 15 of the act, which at 20 or so members cannot represent everybody, and that of course is the body that will select the people who will eventually be on the commission itself. How much representation for seniors do you see on that advisory committee as it is set out in the act?

**Ms Johnson:** Certainly representation from those who are family members, from seniors' groups themselves, but we have to be careful in lumping seniors as one group. There is a wide variety of seniors' groups from the well older adult to the frail or the more frail. Certainly when you get into a position where you are on an advisory committee that has a fair number of meetings, there is a certain frailty that no longer is functional. That is the reality. That is where the ongoing consultation comes in. If you have somebody on the advisory committee who has access, either through a council on aging or that type of a body, to information from the frail, then you are getting that information on an ongoing basis, and I think that is important.

As to a specific number, I do not think we can pinpoint a number of older adults any more than we can the physically disabled. It depends on what particular composition is functional, I think.

Just as important as that is the regional issue. It is very disconcerting for those in southwestern Ontario to have an advisory committee that is primarily from the Toronto triangle area, because the issues are different. Northern Ontario must be represented, because its issues are different. Rural and urban issues are equally as important on an advisory committee.

There are a lot of issues involved in developing it and we understand that. We are not naïve enough to believe that we could choose whom we are going to have based on

one group's input, but certainly there are a number of organizations that have a more widely based input and perhaps they should be considered as at least giving names or suggestions.

**The Chair:** Ms Johnson, Ms Derbyshire, on behalf of this committee I would like to thank you for taking the time out to come down and give your presentation today.

Having no further presentations today, would you like to deal with your motion now, Mr Sterling?

**Mr Sterling:** I believe that all members have received a copy of the motion.

I move that, given that all parties and presenters before the standing committee on justice have acknowledged that major changes are necessary to improve and enhance Bills 74, 108, 109 and 110, the standing committee on justice reconvene for public hearings not earlier than two months after government amendments to these bills from the Ministry of Citizenship, the Ministry of Health and the Ministry of the Attorney General have been tabled and widely circulated, to enable all interested parties the opportunity to study and assess the government's amendments before the committee proceeds with clause-by-clause examination of the bills.

**The Chair:** Mr Sterling moves—

**Mr Sterling:** Just before you repeat that, instead of "given that all parties"—I guess it is the fourth or fifth word in my motion—I would say "given that many parties", because it is not true that all parties raised it or complained about it.

**The Chair:** Mr Sterling moves that given that many parties and presenters before the standing committee on justice have acknowledged that major changes are necessary to improve—dispense?

**Mr Mancini:** Dispense.

**The Chair:** Discussion?

**Mr Sterling:** I must say at the outset that if the members of the government party would prefer to discuss this motion either tomorrow or on Friday—unfortunately I am

not going to be here on Thursday—I would be quite willing to postpone the debate until that time if they wanted to consult and that kind of thing. Would that be your preference?

**Mr Wessenger:** Yes, I think it would be preferable if we could have some discussion.

**Mr Sterling:** Which would be your preference, Friday or tomorrow?

**Mr Wessenger:** Friday, I would suggest.

**Mr Sterling:** Okay. Then I would table the motion at this time and ask that we raise the issue then.

**Mr B. Ward:** Friday morning?

**The Chair:** Friday morning?

**Mr Sterling:** Yes. We are just sitting Friday morning, I believe. We are not sitting on Friday afternoon, I hope.

**The Chair:** We will do it at 12:30, after our last presenter.

**Mr Sterling:** Yes, I think that would be the best time.

**The Chair:** Okay. Mr Malkowski?

**Mr Malkowski:** I just wanted to follow what we were discussing from the morning, to the person who is in the psychiatric institution who wanted to come to speak to us. Whatever happened? We needed a report from the subcommittee just to report back to the whole committee on the outcome of that.

**The Chair:** The subcommittee met and there was no report coming back because we decided to stay with the status quo where he would be notified again that he could come and give his presentation if he so chose. We gave him the option of doing the teleconferencing or submitting a written brief. So there was no report.

**Mr Malkowski:** Okay. That is fine.

**The Chair:** Seeing no further business before this committee, we stand adjourned until 9:30 tomorrow morning.

The committee adjourned at 1634.

#### ERRATUM

No.	Page	Column	Line	Should read:
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Akande, Zanana L. (St Andrew-St Patrick ND) for Mr Morrow  
Mancini, Remo (Essex South/-Sud L) for Mr Sorbara  
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## Assemblée législative de l'Ontario

Première intersession, 35<sup>e</sup> législature

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Wednesday 11 March 1992

## Journal des débats (Hansard)

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### Comité permanent de l'administration de la justice

Loi de 1991 sur l'intervention  
et les projets de loi  
qui l'accompagnent

Chair: Mike Cooper  
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Depuis deux ans, le Journal des débats était numéroté par année civile. Avec ce système, la numérotation des numéros et des pages recommençait au premier numéro de l'année civile, quelle que soit la session ou la législature.

Avec le nouveau système, la numérotation commencée en janvier 1991 s'arrêtera à la dernière séance de la Chambre et des comités de l'actuelle première session. Une nouvelle série commencera le jour de l'ouverture de la deuxième session et des sessions suivantes : numéro 1, page 1. Les rapports des comités seront également numérotés à partir de la première séance de chaque comité pour une session parlementaire donnée.

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# LEGISLATIVE ASSEMBLY OF ONTARIO

## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

Wednesday 11 March 1992

The committee met at 0950 in committee room 1.

### ADVOCACY ACT, 1991, AND COMPANION LEGISLATION LOI DE 1991 SUR L'INTERVENTION ET LES PROJETS DE LOI QUI L'ACCOMPAGNENT

Resuming consideration of Bill 7, An Act to amend the Powers of Attorney Act; Bill 8, An Act respecting Natural Death; Bill 74, An Act respecting the Provision of Advocacy Services to Vulnerable Persons / Projet de loi 74, Loi concernant la prestation de services d'intervenants en faveur des personnes vulnérables; Bill 108, An Act to provide for the making of Decisions on behalf of Adults concerning the Management of their Property and concerning their Personal Care / Projet de loi 108, Loi prévoyant la prise de décisions au nom d'adultes en ce qui concerne la gestion de leurs biens et le soin de leur personne; Bill 109, An Act respecting Consent to Treatment / Projet de loi 109, Loi concernant le consentement au traitement; and Bill 110, An Act to amend certain Statutes of Ontario consequent upon the enactment of the Consent to Treatment Act, 1991 and the Substitute Decisions Act, 1991 / Projet de loi 110, Loi modifiant certaines lois de l'Ontario par suite de l'adoption de la Loi de 1991 sur le consentement au traitement et de la Loi de 1991 sur la prise de décisions au nom d'autrui.

**The Chair:** I call this meeting of the standing committee on administration of justice to order. I just remind you that we have a revised schedule that will be handed out to all the members some time, hopefully first thing, this morning.

B. P. EGIER  
J. R. HEWSON

**The Chair:** I call forward our first presenters, Dr Brian Egier, attending staff, intensive care units, Hamilton Civic Hospitals. Good morning. You will be given a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable could you please identify yourself for the record and then proceed.

**Dr Egier:** Good morning. I am Brian Egier. As mentioned, I am a specialist in intensive care medicine and I practise in Hamilton, Ontario.

This is the first time I have ever spoken before such a committee, and I must admit I made the decision to do so with some trepidation. However, upon examining the proposed Bills 74, 108 and 109, it was very clear to me that there were serious problems in this legislation which would significantly impair my ability to provide timely, humane and appropriate care to the people who depend on me to do so. This is not only my conclusion but that of

many colleagues I have conferred with, all of whom provide tertiary-level referral care of an acute nature to the people of Hamilton and, indeed, central western Ontario.

One of my colleagues, Dr John Hewson, is here with me today.

**Dr Hewson:** I am John Hewson, chief of the department of critical care at the Hamilton Civic Hospitals.

We realize that the focus of these bills is indeed a difficult one, balancing what are sometimes conflicting interests: those of the patients' right to autonomy on the one hand, the care givers' duty to provide appropriate care and assistance, and third, society's responsibility in ensuring for the welfare of its citizens. We applaud the intention of trying to address the complex issues involved, but we also feel very strongly that in practice, many of the proposed solutions will actually do more harm than good. We feel more people are likely to be hurt than protected by these bills.

That is not to say that we find fault with all aspects of these proposed bills, for indeed the formalization of a person's ability to name a substitute decision-maker is welcomed and would indeed help to alleviate many difficulties faced today by patients, families and care givers. However, we believe there are a number of serious flaws in this legislation, and in the next few minutes we will focus on a handful of concerns emanating from Bills 74 and 109, the Advocacy Act and the Consent to Treatment Act, and try to present some examples of the disastrous implications, we believe, of enacting these bills in their present form.

**Dr Egier:** The first area we would like to address is the issue of delays in treatment that will become mandated in instituting necessary therapy for patients. As an example, an elderly woman, previously functioning independently, is brought to hospital by her daughter. She appears unwell and is confused and disoriented. From the daughter's story it is likely that her mother has pneumonia. As is not uncommon in this age group, confusion is an early but totally reversible manifestation of such a severe infection. However, because of her confusion I cannot obtain a valid consent and am therefore unable not only to initiate treatment but in fact even to give her oxygen to alleviate her shortness of breath. I cannot even examine her or get a chest X-ray to confirm my tentative diagnosis.

Instead, I am required by law to call in an advocate to ask this confused, disoriented and toxic woman whether she would like to contest my label of her being incapacitated, because by definition she would not be able to appreciate the consequences of answering yes to the advocate's question; the patient would likely have at least a 50-50 chance of answering yes.

In such a worst-case scenario I would then be unable to offer anything but sympathy to this woman for perhaps as

long as a month while her case winds its way through the bureaucracy. Of course I can always declare the situation an emergency and say that I believe she would suffer serious bodily harm within 12 hours without treatment. The problem here is, what if I cannot honestly meet this arbitrary and unrealistic definition of an emergency? I am then bound to stand by and watch the patient deteriorate either until the bureaucratic process is complete or she is finally so ill that it does become an emergency. The latter is the more likely scenario, but it is reached only by being forced to stand by until the patient is so sick that her life is in immediate danger. That, in our opinion, is immoral. That is not what we physicians are trained to do. Moreover, I do not believe that is what you would want to happen to your mother, your father, your spouse or whomever you hold dear to you.

Unless an emergency is declared, the family in this situation is just as paralysed and impotent as the physician and would likewise be forced to watch the loved one suffer needlessly. This process forces the physician either to distort the law and perhaps lie about declaring an emergency, or to stand back and allow patients who depend on their care givers' professionalism and simple humanity to deteriorate while the bureaucratic process edges onwards.

**Dr Hewson:** Example 2: Let's say we have in fact declared an emergency in the case of this woman with pneumonia. Her lungs are failing and we must put her on a mechanical ventilator lest she otherwise die. Part of our course of therapy would be to sedate her in order to make her comfortable and allow us to help her. But alas, at 72 hours our ability to treat her on the basis of an emergency ends. Do we declare another emergency or do we wake her up and take her off the ventilator and try to reassess her competence at the risk of allowing her to deteriorate? If she is still incompetent, do we then have to call in an advocate and return to the same dilemmas mentioned before? At the very least the proposed law is extremely unclear; at worst it is incompatible with the realities of providing safe, competent and humane care to very large numbers of people.

**Dr Egier:** Even if the patients in these examples fortuitously happen to say no to the advocate perhaps precious hours would have elapsed, or at the very least the patient is left in pain, discomfort and danger. Moreover, the slowness of the process would impact on the availability of scarce resources for other patients awaiting help and assistance. These cases point to a fundamental flaw in the rationale behind the job to which the advocate is directed.

If I may, I will just stand up and point out a problem on a chart. My apologies for the size of the writing on it. I will take you through the scenario.

**Mr Poirier:** It is a doctor's handwriting, right?

**Dr Egier:** This is my very best handwriting.

The patient has been declared incompetent. The advocate is called in. The advocate says to the patient: "You're being labelled as being incapacitated. Would you like to challenge this finding?" There are two possibilities.

The first is that the patient is truly competent and has been unjustly or inappropriately labelled as being incom-

petent, in which case presumably the patient will say, "Yes, I would like to contest this," an appeal process is undertaken and hopefully the system will work and that patient will be protected. This is the group of people that I believe is trying to be addressed by this legislation.

There is another group of people, however, that really is incompetent. The problem is that by the fact that they are truly incompetent, by definition they are also going to be unable to appreciate or understand the implications of that label and the consequences of the response they are being asked to give to the advocate. In other words, they do not understand the difference between saying yes or no to the advocate's question: "Do you in fact want to contest this?" Therefore they have at least a random chance of 50-50 in answering yes or no to the advocate's question. In fact, I suspect it will be a little bit more than 50-50 who say yes, because subtly or not so subtly the advocate may well bring a bias into that room where he or she is alone with the patient, and that bias is very easily transmitted. Let's say the patient says, "No, I don't want to contest this." There is still some delay, perhaps in the course of hours and hopefully not too much more than that. Is it optimal, is it fair, is it humane to the patient? These are questions we must ask.

But there is another group of patients that in its incapable state fortuitously happens to not understand the implications of saying yes. In fact, although they are truly incompetent and will ultimately be found to be incompetent, they say, "Yes, I want to contest it." It is in this group of patients where there is extraordinary potential for incredible harm being done from the standpoint of their safety, their comfort and their dignity.

The problem is that the blue and the red groups of patients will extraordinarily vastly outnumber the green patients, perhaps by orders of magnitude. In other words, to coin an old phrase from medical history, the cure is worse than the disease.

#### 1000

While there may be specific types of situations in which greater protection of vulnerable people is needed, the breadth of these bills does not allow for a differentiation between the many different types of interactions between patients and their care givers. In many of these instances this legislation could harm more people than it might help.

**Dr Hewson:** Costly expansion of the bureaucracy: While significant amounts of money will be needed to create and run such offices as the Advocacy Commission, including the advocates themselves, in order to provide for equitable and timely access to anyone anywhere within Ontario, we would like to mention here only the office of the public guardian and trustee, indeed to concentrate only on the relatively narrow function of gathering and presumably processing and reviewing documentation on those patients who have met the criteria for emergency intervention.

The sheer volume of paper flow from this function alone would be staggering. We estimate that in Hamilton alone, and considering only intensive care unit admissions,

there would be approximately 2,000 to 3,000 patients per year, each of which would involve at least 10 or more independent health care practitioners, thereby producing roughly 20,000 to 30,000 submissions per year, or 60 to 70 per day, or 3 per hour 24 hours a day, and that is only in Hamilton.

That, I remind you, is only a limited proportion of the applicable patients in only one midsized city in this province. We would not pretend to be able to calculate the cost of such an extension and the ongoing cost of maintaining your bureaucracy mandated by such legislation. The next question of course is, what would be done with such massive documentation and for whose benefit is this bureaucracy functioning?

**Dr Egier:** Substitution of an adversarial, dictatorial process for a consensual discussion: Decisions regarding care for an individual can sometimes be difficult and involve varying perceptions, values and priorities among both care givers and those who know the patient and are attempting to speak on his or her behalf. When such problems arise, we feel the best way to resolve such difficulties is usually via discussions between those involved in the care of the patient with their attendant expertise and goodwill, and the family or other substitute decision-makers who in turn bring to the discussion a knowledge of the patient's life and values as well as a commitment to the best interests of their relative or friend. In almost all such cases, common sense, goodwill and open discussion will ultimately result in decisions with which all involved are comfortable. Occasionally outside help, such as through the use of clinical ethics committees, for instance, can be utilized to everyone's benefit.

We are seeing here a proposal to take decisions away from those at the bedside, including in particular family, and to substitute instead the impersonal, hands-off and perhaps dehumanizing alternative of a bureaucratic committee. Furthermore, rather than arrival at a consensus among family members who initially may have honestly different perceptions of what is right, the solution proposed here is a dictation by a bureaucracy more concerned with making a decision than with any possible long-term emotional damage to the lives of the survivors.

While the personal, involved, real-life approach is not always perfect, we believe our goal should be to work together to better that process rather than to substitute an impersonal, adversarial process in its place. I would rather have people with common sense and goodwill deciding on my behalf at the bedside and seeing me as a person, appreciating my unique circumstances and feeling for my predicament there than well-meaning but distant, detached and unknowing bureaucrats deciding by decree over my future at some distance.

An individual's rights are not best protected and his or her best interests are not best endured by dehumanizing this process.

**Dr Hewson:** Organ transplantation: We are concerned about the specific inability of substitute decision-makers to consent to organ donation for transplantation. Unless another act would supersede Bill 109's prohibition—in which case,

why is it there?—then the detrimental effect on the entire transplantation program in Ontario would be devastating.

**Dr Egier:** Confidentiality: Beyond the extraordinary rights of entry afforded to advocates, there is in addition a right of access to the records of patients which can be accomplished via two routes. First, the patient can consent to the advocate's access. That is fair enough. However, the advocate may alternatively gain access via a directive from the commission without patient consent and indeed may involve access to information on patients who have not even been involved with the advocate or, even worse, have refused such involvement. The commission may authorize such access when such information, in its view, may be useful to further political or social goals. Such goals, of course, may not be shared by the patient.

We have here a fascinating but frightening paradox. The purpose of this legislation is to further the rights and dignity of vulnerable individuals. In practice, while some individuals may well benefit, the legislation also provides for an extraordinary infringement upon the civil rights of other individuals. In fact, the individual almost ceases to exist, becoming instead an example of a disability, a disease or a disorder. Individual rights to privacy will become potentially subservient to the political and social agendas of special-interest groups.

Beyond these incredible powers of search and seizure, the rules surrounding secrecy regarding the information gleaned from the advocates' or the commission members' work remind me of the saying that, "A secret is something that you tell one person at a time." Such information could spread quite widely, limited only by what the commission regards as appropriate for its political and social agendas.

**Dr Hewson:** In summary, we have highlighted issues of delay in treatment, costly expansion of the bureaucracy, substitution of an adversarial, dictatorial process for a consensual discussion, organ transplantation and confidentiality.

To conclude, while recognizing that our health care system is indeed not perfect, we feel that these proposals would stand to hurt more people than they might help. There is a basic principle in medicine that the cure should not be worse than the disease; first of all, do no harm.

We believe these proposed bills should be withdrawn and a process initiated which involves input from all the players in the system, with their varying perspectives and expertise. We believe there are viable and workable means of enhancing the protection of individuals but that these bills are not the answer. We believe we must go back to the drawing board and broaden the base of contributors, building upon expertise, experience, goodwill, common sense and even trust. Thank you. We would be happy to receive any questions.

**The Chair:** Thank you. Each caucus has about four minutes for questions and comments.

**Mr Poirier:** You started off by saying that you somewhat hesitated about coming forward. After reading your presentation, thank God you did not hesitate and you did come forward. I think the points you made have been made by many, many, many health professionals around—nurses, doctors and whatever—and we sure do not need

much more convincing to try and put ourselves in your shoes to find out that this is going to be a hell of a nightmare. I do not blame you for coming forward.

Could you expand a bit on the organ transplantation issue, because I had presented a private member's bill that created the MORE system to get organ transplants, the multiple organ retrieval and exchange, and if I am not mistaken, you are the first ones to bring this forward, and this is quite a nightmare. How do you see it in the practicality? Could you expand a bit on that point, number 4 on page 9?

**Dr Egier:** Sure. I have it in front of me, so I will do it. In Bill 109, I guess it is called section 15, it states that,

"Nothing in this act authorizes a health practitioner to perform any of the following procedures on a person who is incapable with respect to the procedure:

"1. A procedure whose primary purpose is research.

"2. Sterilization that is not medically necessary for the protection of the person's health.

"3. The removal of regenerative or non-regenerative tissue for implantation in another person's body."

In our reading, that makes it impossible to get a consent from anyone for donation of organs.

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**Mr Poirier:** I cannot imagine that is what the government's intent was. Surely this is the type of support you have. I would not mind getting a response from the parliamentary assistant on that. We have a lot of work to do still in organ transplants; it is not widely accepted and widely available yet, and if this is going to further reduce it, this is extremely upsetting news to you. Maybe the parliamentary assistant, after getting some sound advice from legal counsel, will be able to give us some ideas.

We will let him consult first, but while they are waiting for the answer, I just wanted to put a smile on your face. I am an amateur calligrapher, and this is the first time I have been able to read a doctor's handwriting. I am quite impressed. I did not know that doctors could write. This is really neat, so I must congratulate you. I think I will keep a copy of this and frame it.

**Mr Wessenger:** I believe you have a question for me?

**Mr Poirier:** Yes, I do. You were not able to understand, I guess.

**Mr Wessenger:** No. We were discussing probably the issue you wanted to ask the question on, but anyway.

**Mr Poirier:** Okay, it is the organ transplantation issue the doctors have brought forward.

**Mr Wessenger:** Let me just say that under the Human Tissue Gift Act you cannot have an organ donation from an incapable person, quite rightly so, I think. I would be very surprised if the doctors are saying we should change that act to say that an organ transplant can be taken from an incapable person. Certainly once the person is dead the organ transplant can be given by the executor, and that is the normal situation, and a capable person, of course, can consent to an organ transplant. This is the existing law, and I would be surprised if the medical practitioners here would be advocating to change that existing law.

**Mr Poirier:** What if some person who is deemed to be incompetent in the emergency room comes in and has his or her driver's licence consent form, but they seem to have that person as incompetent?

**Mr Wessenger:** That is after death. That of course is perfectly legitimate.

**Mr Winninger:** That is when you are dead.

**Mr Wessenger:** We are talking about when people are alive prohibiting organ transplants.

**Mr Poirier:** Okay. Your response?

**Dr Egier:** It is very clear that the only people we would in fact be looking to organ donorship in are people who have in fact been declared brain-dead.

**Mr Wessenger:** There is nothing in this act that prohibits that. This is just relating to live people who are incapable, not dead people.

**Dr Egier:** I was not aware of anyone asking for organs from live people, and therefore I wonder why it is in there in the first place. I am not aware of anyone anywhere seeking organs from live competent or incompetent people.

**Mr Winninger:** What about donations?

**Mr Wessenger:** It is there very obviously because with capable people you often have a consent, for instance, from one relative giving a kidney to another relative, and that happens in several instances, as you are aware, like a kidney transplant. What this would prohibit is of course that kidney transplant from—recognizing the fact that some legal act had taken a kidney transplant from an incapable person to transplant it to a capable person.

**Mr Poirier:** Fair enough.

**Mrs Sullivan:** Just as a point of order, Mr Chairman: I wonder if as these hearings go along, because there has been quite enormous misunderstanding about this section of the act, when the recap is being done, the parliamentary assistant would ensure that there is solid briefing of the entire committee relating to this section and indeed the need for that particular section of the act, given that part of it is covered by the Mental Health Act.

**Mr Wessenger:** I certainly think it would be an excellent idea after the public hearings and before we go into clause-by-clause that we have a full briefing on each act before we go into the clause-by-clause.

**The Chair:** Further questions or comments?

**Mr Sterling:** I found your presentation quite good, because it not only dealt with the technical problems of the act in terms of what is treatment etc, but it also dealt with the greatest fear I have, that it is going to gum up the system so badly that the system is not going to be able to treat as many people as it has in the past. We know how there are problems with access to the system at this time.

Given that some of the technicalities I think will be remedied in Bills 108 and 109, is there anything you could suggest to the government to narrow the focus of the advocate to the cases where there might be some justification for having an advocate intervene into the health care situation?

**Dr Egier:** I very much wanted to come today with some suggestions to be concrete and helpful. The problem

is that, as you clearly realize and as we fully appreciate, these are very complex issues, and I hesitate to sort of spend 15½ seconds trying to sum up very complex and difficult problems. Clearly that is one of the major issues: How can we in fact try to identify the green patients so we can help them and we can protect them but at the same time not hurt the vast majority of people going through the system, who in fact do not fall into that category at all. I do not have an easy solution to how to do that. I guess I would first ask Dr Hewson if perhaps he has a suggestion, and second—perhaps this is little bit unusual—in the process of what I hope will be a reassessment and rewriting of these bills, I would certainly be more than happy to offer my services in terms of the perspective of acute care medicine to think these things out, to discuss them and to perhaps come up with some more practical and fairer kinds of solutions.

**Mr Wessinger:** Have you read or are you aware of the comments the Minister of Health made to this committee on December 10, 1991?

**Dr Egier:** No.

**Mr Wessinger:** Okay, perhaps just for clarification I should indicate to you that the Minister of Health said with respect to the emergency provisions, first of all, the 12-hour period should be deleted. She has also said that the emergency provision should be amended to permit alleviating severe pain, and third, that the emergency provision should be amended to provide that emergency treatment will not be discontinued in those exceptional cases where no substitute decision-maker is available within the 72-hour time period. So those are three areas where the provision will be amended.

**Mrs Sullivan:** Let's have those amendments so everyone can see them.

**Mr Wessinger:** The Minister also indicated that she would welcome suggestions for improving and clarifying the definition of "emergency," so if you have any other specific suggestions in this regard, we would certainly appreciate receiving them.

**Dr Hewson:** I do not have any quick-fix answers, likewise. Perhaps one way to try to define that group that is truly competent but being labelled incompetent, which I believe is the group towards which this legislation is directed, would be to try to examine the sources whence arose the concern over this as a social issue in the first place. Clearly there are segments in society who have decided that there was a need for this type of legislation, and perhaps examination of the root sources that led to the concern might help define a little bit more clearly the subareas within the health care system in which there appears to be a problem relative to autonomy and competence and incompetence.

I guess the concern Dr Egier and I have is that this appears to be an exceedingly broad net for a problem the magnitude of which we have really very little information on. I have heard nothing in the popular press to help me understand the magnitude of the problem, and maybe we need to examine the problem itself in a little more detail to perhaps come up with a somewhat more finely tuned solution.

**Mr Sterling:** Mr Chairman, on that specific point, I asked the Ministry of Health, I believe three and a half or four weeks ago, for this very type of information and have not received a response from them as to the statistical evidence of abuse problems, of vulnerable people being taken advantage of, and I was just wondering when I might expect the reply.

**Mr J. Wilson:** I think if you check the record, Mr Chairman, some two weeks prior to that I asked a similar question.

1020

**The Chair:** I think we have an answer from legal counsel here.

**Ms Spinks:** I believe that question was, in fact, addressed to our ministry, the Ministry of Citizenship. The information you have requested is being completed and I believe they want it to be as full and complete as possible. It should be available in the next day or two.

**Mr Winninger:** I was interested in your chart and I was also interested in a statement made on page 10 that, "The individual almost ceases to exist, becoming instead an example of a disability, a disease or a disorder." In fact, we have seen a lot of the walking wounded come through here in the past few weeks, people who have been lobotomized, people who have received electroconvulsive shock, people who are suffering the deleterious effects of drug therapy even now.

What I heard from their evidence was that these people felt victimized. These people felt that through the benevolent paternalism, if you will, of the medical profession they were given treatment they never knew the consequences of, the side-effects of, the long-term effects of. Surely you would agree with me that the intervention or assistance of an advocate is a small price to pay to ensure that these vulnerable individuals will never have to go through the kind of psychiatric abuse they have suffered in the past.

**Dr Hewson:** I think it goes without saying that I would agree 101% with every word in your comments. My further comment to your statements, again, with which I fully agree, suggest to me that perhaps, as a furtherance of my comments a moment before, the area wherein the problem may be lying may be related more to areas of psychiatric therapy and that aspect of medicine, for example, than the more organically related things such as a car accident or pneumonia or issues along those lines.

I guess that is in keeping with my comments of a few moments ago suggesting that maybe we need to see which areas of health care appear to be the ones in which these problems have arisen and perhaps tailor the legislation to deal with the areas where indeed there are true problems rather than perhaps casting a net that is sufficiently wide to pose problems in other areas of health care where this type of issue is not an issue.

**Mr Winninger:** You might want to talk to Dr Cleghorn, who spoke yesterday, because I do not think he would agree.

**Dr Egier:** I do not believe we are blind to problems in the system. There is no question that there are some

individuals who have in fact suffered under our present system. There is no question that there are cries for help.

My concern is your comment that surely an advocate is a small price to pay. I believe that perhaps we should be asking that question of the countless thousands of people who will suffer badly, perhaps because of an attempt to correct a problem which may be relatively isolated and may be identifiable and more clearly dealt with rather than a broad blanket across the entire health care system of this province, which may, as I have mentioned, help some people and may badly hurt many more.

**Mr Winninger:** Just one note then. It was not just psychiatric evidence. We did have a lady here Monday morning who was, she said, a perfectly normal healthy baby in England until she received a particular vaccine. As a result, she came here in a wheelchair.

**Dr Egier:** I am not sure I want to get into a debate about specific patients.

**Mr J. Wilson:** What has that to do with having an advocate?

**Mr Sterling:** She would not have an advocate—

**Mr J. Wilson:** She would not have an advocate because she was perfectly—

**Mr Winninger:** A question has been put to me. She suggested that advocates could provide assistance to children in those circumstances. That was her proposal.

**Mr J. Wilson:** And at the end of her presentation she suggested you scrap the bills.

**The Chair:** Thank you, Mr Winninger. Dr Egier and Dr Hewson—

Interjections.

**The Chair:** Order, please, Mr Wilson. Dr Egier and Dr Hewson, on behalf of this committee I would like to thank you for taking the time out this morning and coming and giving us your presentation.

#### VISION COUNCIL OF CANADA

**The Chair:** I would like to call forward our next presenters, from the Vision Council of Canada. Good morning. Just a reminder that you will be given a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, please identify yourself for the record and then proceed.

**Mr McArthur:** Mr Chairman and members of the committee, good morning. My name is John McArthur and I am here this morning in my capacity as the president of the Vision Council of Canada.

The Vision Council of Canada is a non-profit organization representing the retail optical industry in Canada. Our member companies account for a significant number of retail optical outlets in Ontario. In 1991 VCC members and supporters employed over 1,000 people in the province, including more than 25% of the province's licensed opticians.

The VCC's mandate is to ensure that quality eye wear products and services are available to the public at a reasonable cost.

The focus of our brief this morning is Bill 109, An Act respecting Consent to Treatment. Bill 109 lists in its schedule, in addition to professionals covered by the Health Disciplines Act and other medically related acts, the Ophthalmic Dispensers Act. This is the legislation governing our optician employees.

As stated in a memorandum written by Ministry of Health assistant Deputy Minister Michael Ennis on August 19, 1991, the subject of which was advocacy, substitute decisions and consent to treatment, Bill 109 "sets out clear rules on consent to treatment administered by all health care providers in all health settings. It affirms the right of everyone to be fully informed when making health care decisions, enables people to express their wishes in advance with regard to treatment, and ensures that decisions made on behalf of incapable persons are respectful of their rights."

We believe that the government's intention with this act to enshrine the rights of individuals concerning health and medical care decisions in legislation is commendable and worthy of support. Our concern, however, lies in the expansive scope of the legislation and the potential medical judgements that the legislation would require of our members' optician employees in commercial establishments.

Opticians receive no formal medical training and are not health care providers in the traditional sense. Their course of study or apprenticeship does not include training to determine an individual's mental capacity. Opticians do not perform eye examinations, nor do they prescribe corrective eye wear. They do not work in a health care setting.

Opticians are professional technicians who provide glasses or contact lenses on the basis of a prescription written by an optometrist, an ophthalmologist or a general practitioner, individuals who are licensed to examine and prescribe corrective vision apparatus.

Suppose for a moment that an individual with Alzheimer's disease arrives in a VCC member retail outlet bearing a prescription provided by an authorized prescriber. Is it not the prescriber's responsibility, under this act, to make his own decision on this individual's capacity before providing treatment, ie, examination of the eyes and provision of a prescription? If so, should that decision not be valid for the purchase of the actual glasses themselves?

As written, Bill 109 could require the optician to overrule the prescriber's decision that an individual is capable with respect to the very treatment for which the OD or MD has issued a valid prescription and to not fill the prescription should that individual display any sign of incapacity. It would require the optician, with no medical training, to overrule the judgement of an individual who is qualified to make these decisions. If a health practitioner who orders tests or X-rays is responsible for ensuring that consent has been obtained, should not the same decision-making structure apply to health practitioners who prescribe corrective eye wear?

Another factor we believe should be considered is the manner in which many retail optical outlets operate. They

are not structured like medical offices. There are no private offices, nor is there likely to be an area which would allow a private discussion with a customer about a possibly very sensitive and personal issue. In addition, in many instances the first contact an individual has when he or she enters an optical establishment will be with a frame stylist, or a non-optician in any event. These lay individuals are not covered by the acts listed in the schedules and also have no medical training. Their function is to assist in the selection of a pair of frames which will be aesthetically pleasing, to ensure that the colour and the shape of the frame are appropriate.

1030

Therefore in many retail optical outlets it will only be later in the process, after the person has already selected his frames, that an optician will become directly involved. This could lead to a situation where a customer who has already selected his glasses is then told that there is a problem with his capacity to have made that judgement.

The VCC believes the responsibility to determine an individual's capacity does not appropriately rest with an optician. We believe that opticians should not be required to make judgements for which they are not trained, nor should they be required to potentially overrule decisions made by health care practitioners. We believe it is the obligation of health care providers—the optometrists, ophthalmologists or general practitioners—to determine their patients' capacity and/or whether the patient is incapable with respect to the examination and the dispensing of the eyeglasses or contact lenses required by the prescription. Once a prescription has been rendered by an authorized prescriber, the judgement required as to an individual's capacity should have been made under the requirements of Bill 109.

The VCC believes, therefore, that individuals covered by the Ophthalmic Dispensers Act should not be held accountable under Bill 109. The instances in which an obviously incapacitated individual will seek to fill a prescription for an eye care product and not be accompanied by a person who can provide consent as set out in section 16 of the act will also likely be very rare. In those rare instances, common sense should dictate appropriate action, which may simply be a telephone discussion with the prescriber or a referral back to the prescriber.

The Vision Council of Canada is fully prepared to work with officials of the Ministry of Health to clearly articulate what form that appropriate action should take. We are, as well, prepared to take whatever steps are necessary to advise our employees of consent to treatment issues. We simply do not believe that it is wise, appropriate or necessary to require it under Bill 109, and we ask that you exempt the Ophthalmic Dispensers Act from this legislation.

Thank you very much.

**Mrs Sullivan:** I have indicated to you previously, Mr McArthur, that I concur with the point of view you have put forward. I think the situation of the Vision Council of Canada raises issues that indeed the Minister of Health did speak to before the committee in her initial presentation, indicating that the schedule to the act would have to be

changed because the definition of the health practitioners to whom Bill 109 will apply is going to be maintained in a schedule.

Unfortunately this leads to an entirely other area, because as we have had no other guidance from the minister relating to where the new self-governing regulations under the new legislation will fall in, we see other deliverers of services that are associated with health care affected in the same way, by example, dental technologists—denturists perhaps may be more of an appropriate example; medical laboratory technicians, X-ray technicians.

The issue here is, where is the responsibility for determining that consent is appropriate and available, who has paramouncy in gathering that consent, and does consent have to be obtained at every step along the way during the course of treatment? These matters are very unclear. Health professionals are extremely concerned about what could simply be a drafting error or in fact could be an intent, and nobody knows.

I think it is incumbent upon the parliamentary assistant in Health, who is carrying this bill, to put before the committee the minister's current thinking on which professions will be affected by this legislation, what is going to be included in the ultimate schedule under the regulations, and what kind of public consultation process there will be in determining whether indeed it is appropriate that a profession be included in that schedule.

We have heard a telling argument from the Vision Council of Canada relating to the scope of their practices. There are certainly other areas which must be included. Given that this act was first introduced in the House in May, that the Regulated Health Professions Act was dealt with in the House last Autumn, surely it is time the minister was somewhat more forthcoming in relationship to her own intent.

The other question that is raised by this presentation is the significant amount of important decisions in all these three acts which are being made by regulation and are not being made clearly and openly in a public forum by statute. This is a matter of concern that we have been raising from the very beginning, going back right to the definition of advocacy services, the mandate and scope of an advocate in Bill 74, to other matters that will only be dealt with by regulation. We do not feel that is an adequate method of dealing with something that affects the life of every single person in this province. Thank you for your presentation.

**Mr McArthur:** Thank you.

**Mr Sterling:** Could I ask the parliamentary assistant why he would want to include this group under Bill 109?

**Mr Wessinger:** I do not think it is fair to say there has yet been any decision made on who will be included under the schedule. I believe the original intention was to include practitioners under the Health Professions Act, but certainly we are listening to the presentation made by the presenters today and that will be taken into account when the decision is made on these issues.

**Mr Sterling:** Of course, if you accepted our amendment to subsection 1(1), which we introduced two or three weeks ago, it does not include a prescribed thing, a treatment.

Therefore, I am sure, although maybe the pharmacists recognized the problem, they probably are faced with a larger problem than this group is. What are you going to do with regard to this group, may I ask on behalf of the pharmacists? What are you going to do with the pharmacists?

**Mr Wessenger:** Some of the things described in the brief would probably not be under the question of treatment. Certainly the filling of a prescription by an optician would not be treatment, in my opinion, even under the existing wording of the legislation. The fitting of the glasses might be considered treatment; I cannot see how the filling of the prescription would be a treatment.

**Mr Sterling:** I understand the pharmacists have asked to come in front of this committee later this month. If you can categorically say that filling a prescription is not going to be included under Bill 109, then I suggest we convey that to them and maybe it will save them a trip. Are you categorically telling us that?

**Mr Wessenger:** I am not in a position to advise the committee with respect to the matter of who will or will not be included under that.

**Mr Sterling:** It is a pretty major problem here.

**Mr Wessenger:** That is the reason we are having these hearings, to hear from groups who feel they should not be included under the provisions, and that is what the representatives have asked today.

**Mr Sterling:** That is a weird way to bring legislation in. You say, "Everybody in the world is covered under this legislation, but come in and complain you do not want to be under it." I mean, surely to God there is some onus on your part to say, "You are covered under this legislation." Make your decision.

**Mr Wessenger:** I think, with respect to this particular profession, there is an aspect of touching, or a physical aspect in fitting glasses. That is a consideration that has to be taken into account in making a decision.

**Mr Sterling:** But do you really want your advocates on their premises? I mean, basically, is not the ultimate concern of the government that a vulnerable person is going to be taken advantage of, is going to be maltreated, is not going to get the proper treatment? Let's be somewhat practical about what we are doing here. What on earth can happen on their premises that would in any way hurt any individual in Ontario? Tell me.

1040

**Mr J. Wilson:** It certainly did not come out during the RHPAs.

**Mr Sterling:** You have to be practical when you run a government, too, you know. You have to collect the bucks to pay these guys to go in and deal with it. Do you want these people waiting two or three months for their glasses?

**Mr Wessenger:** I think when we go to the clause-by-clause that—

**Mr Sterling:** We want decisions now.

**Mr Wessenger:** No. The process now is that we are hearing deputations. The decision-making process comes when we deal with the clause-by-clause.

**Mr Sterling:** Listen. You owe the respect to members of this committee not to waste their time with submissions that are not going to be relevant in the long run. Therefore, you have made this group come down this morning, and if in fact they are not going to be considered and it is not a real concern, then you do not have the right, in my view, to waste our time and waste the time of the various people in front of this committee when in fact there is no relevance with regard to the legislation.

**Mr Malkowski:** On a point of order, Mr Chairman: This is not a debate.

**Mr Sterling:** It sure is.

**Mr Malkowski:** We are here to hear from the presenters. Let's not get into our own squabbles. We are here to hear from the witnesses this morning, if we could focus our attention on that.

**The Chair:** That is not a point of order, Mr Malkowski.

**Mrs Sullivan:** On a point of order, Mr Chairman: The act, in the definitions in Bill 109, indicates that the consent to treatment provisions will apply to persons who are registered or licensed under a statute which is listed in this schedule. The current schedule to the act includes ophthalmic dispensers. That act is no longer in force after the RHPA. The new schedule of self-governing health professionals applies to many more professionals. The minister has indicated that the act and the schedule will change to include self-governing health professionals. In this case, the Opticianry Act would apply. The second section says the act applies to a person who is a member of a prescribed category.

The parliamentary assistant is telling us today that we do not know to whom this act applies and that there is no information forthcoming on which kinds of practitioners or which other categories of people are subject to the provisions of this act and have to follow the terms of this act. This is absolutely extraordinary.

**The Chair:** Thank you for that information, Mrs Sullivan.

**Mrs Sullivan:** I think it is incumbent upon the parliamentary assistant to inform the committee and the public who is subject to and who must follow the requirements of this act.

**Mr Wessenger:** The act as presently drafted is quite clear. It sets out in the schedule the acts that are covered. The new acts are not yet proclaimed and consequently the schedule as it exists is inappropriate at this stage.

**Mr Sterling:** A total disregard for people's time, money and efforts. This is ridiculous. I do not know how you argue that these people should be included. Why do you not exclude them? You are the parliamentary assistant. You get paid for being the parliamentary assistant. Make a decision. Do something. Call your minister.

**Mrs Sullivan:** Who else is going to be added?

**The Chair:** Mrs Akande.

**Ms Akande:** Thank you very much for the presentation. I recognize that opticians are not supposed to prescribe glasses—or do they?—and they respond to the prescription as written by an optometrist or an ophthalmologist.

I do know, however, that there are adjustments frequently made in the prescriptions, perhaps illegally.

**Mr McArthur:** I am not aware of that.

**Ms Akande:** Then let's put it this way: If there are adjustments made in the prescriptions and those are made in the prescriptions of people who are vulnerable, it is found to be whose fault? Who would you think would be at fault in a case like that?

**Mr McArthur:** It strikes me that the question is trying to determine something that is hypothetical. An optician's role formally is to provide eyeglasses, and lenses specifically, that correct vision accurately according to the prescription written by an optometrist or an ophthalmologist.

**Ms Akande:** I am aware of that, but I am concerned about practice.

**Mr McArthur:** That errors could happen?

**Ms Akande:** That errors do happen and that when they do happen someone must assume responsibility if the person is vulnerable.

**Mr McArthur:** Yes.

**Ms Akande:** I am asking who you think that person should be.

**Mr McArthur:** I think if an optician does not have a pair of eyeglasses fitted that do accurately reflect the prescription, the optician is liable and responsible.

**The Chair:** Mr McArthur, on behalf of this committee I would like to thank you for taking the time out this morning and coming to give us your presentation.

**Mr McArthur:** Thank you all very much.

**The Chair:** In light of the cancellation we have had and the fact that the presenter is not here, we will recess until 11 o'clock.

The committee recessed at 1046.

1104

#### CITY OF TORONTO DEPARTMENT OF PUBLIC HEALTH

**The Chair:** I call this meeting back to order. We have a presenter from the city of Toronto department of public health. Good morning. Just a reminder that you will be given a half hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, please identify yourself for the record and then proceed.

**Ms Bean:** Thank you. I am Bonnie Bean. I am the supervisor in the department of public health, city of Toronto, and I am here to present our response to Bill 109.

I do not know whether you have received copies of the brief, but I intend to read part of it and rearrange the recommendations to follow my statements and make a few off-the-cuff remarks as well.

The city of Toronto department of public health supports the overall intent of this legislation to clarify the consent to treatment process, provide patient advocates and facilitate informed consent. Bill 109 can improve the

delivery of health services by clarifying the role of providers and protecting the rights of vulnerable patients.

We want to address two significant concerns we have with Bill 109, an Act Respecting Consent to Treatment. On the last page we have a minor concern that I will address later.

The first significant concern is the selection of the age of 16 for capacity to consent, which we believe constitutes an unnecessary and arbitrary barrier to equitable access to such vital services as birth control, pregnancy testing and counselling, abortion, and testing and treatment for sexually transmitted diseases for young people. Any consequent restriction in access could have serious long-term effects.

The second concern we have is that the definition of treatment is too broad and could jeopardize education, counselling and screening programs, all vital to public health preventive and health promotion strategies.

As you may know, the city of Toronto department of public health is one of the largest health units within the province of Ontario. Our programs and services are based on principles of equitable access to basic health care, health promotion and disease prevention.

One of our major program areas is sexual and reproductive health. Program components include sexuality education in schools, clinical services specializing in family planning and sexually transmitted diseases, and diverse community-based health initiatives and services. Overall, our programs are guided by Ministry of Health mandatory health programs and services guidelines which specifically outline key objectives in these health areas.

Preventing the spread of STD, including HIV, reducing the number of unintended pregnancies and promoting services based upon informed decision-making in the areas of contraception, pregnancy, abortion, sexuality and reproduction are major program foci.

High rates of teenage pregnancy and STD among teens have made adolescents a key target population for this programming. Many youth are—and if you are reading along with me, you will note the phrase “sexually active”; I prefer to be more specific and insert “having sexual intercourse” before the age of 16, the age that Bill 109 would automatically allow them capacity to make treatment decisions.

The 1988 Canada Youth and AIDS report found that one in five 14-year-olds and one in two 16-year-olds have had sexual intercourse. Reaching this population with effective education and medical services is an important public health objective.

Section 8 of this legislation presents the most serious concern from our point of view. This section establishes 16 as the age of capacity to consent regarding treatment decisions. It presumes that anyone under the age of 16 is incapable of giving consent. Health professionals can rebut this presumption.

We believe this will have a detrimental effect on the provision of health care to young people. First of all, the legislation is not clear about what the rebuttal process entails. In the absence of clear guidelines, many health professionals could be intimidated from providing services

because of the uncertainty about their responsibilities and liabilities. Even if an explicit rebuttal procedure is established, many professionals, we fear, simply may not bother to go through it. In effect, whether intended or not, age 16 may simply function as an arbitrary cutoff.

The fear is that, regardless of the patient's understanding of the issues involved and regardless of his actual physical, emotional and overall development, many doctors will not want to take a chance. This concern has been expressed in professional medical journals and by leading physicians and public health experts.

A recent parallel case graphically demonstrates the fragility of access to services for sexual and reproductive health—physicians' reactions to the proposed federal law on abortion. In anticipation of the legislation passing, many physicians had withdrawn their services throughout 1990 and many more said they would do so when the bill became law. This reluctance to provide services created inequitable and, in many places, non-existent access to abortion. We feel that we could be facing a similar circumstance here.

What will the impact be on young people if access to sexual and reproductive health care services and counselling is restricted? We think the consequences will be very serious indeed. The options for many young people could be stark: having to shop around to find someone who is willing to provide service, lying about one's age or, more likely, doing without medical service and care.

#### 1110

In the areas of sexual and reproductive health, this can have serious consequences; these include high rates of teen pregnancy, infection from sexually transmitted diseases, abortion, pelvic inflammatory disease, infertility and low-birth-weight babies. Each of these involves critical physical, psychological, social, emotional and economic costs.

In 1989, approximately 14,000 15- to 19-year-olds became pregnant in Ontario. There were about 180 pregnancies for 10- to 14-year-olds.

According to a National Health and Welfare advisory group on STD, the highest age- and sex-specific instance of reported gonorrhoea occurred in females 15 to 19 years of age in 1989. Seventy three per cent of all chlamydia infections were found in the same group.

The incidence of chlamydia for 10- to 14-year-old girls in Ontario was 30 per 100,000 in 1989. This has been increasing since 1985.

Delay in receiving treatment for STD increases the chances of such negative long-term health consequences as pelvic inflammatory disease, infertility and low-birth-weight babies.

We recommend removing the reference to age and retaining the current common-law practice. This allows an individual to consent to medical treatment if he or she has understood and can appreciate the nature and consequences of the treatment. This allows young people to make independent medical and health care decisions to their full capacity in conjunction with their health care professional; the health provider makes a judgement in each individual case.

Our experience, through talking to young people in schools and family planning and STD clinics, is that the ability to receive confidential services and the ability to make independent decisions affecting their own health are critical factors in their willingness to come into the public health system. In my opinion, when young people are treated as mature and capable of making their own decisions they in fact become more mature and able to make wiser decisions.

Bill 109, as it is currently proposed, creates a further unnecessary barrier which may deter young people from seeking health services. The ministry has not offered any convincing arguments for why a reference to a specific age is necessary. Given the significant concerns expressed by front-line providers and public health experts and given the serious consequences for young people's health of any restriction of access to sexual and reproductive health services and counselling, the prudent course, in our opinion, is simply to delete the age requirement.

Removing this age requirement will not by itself ensure equitable access to health care for all young people. The provincial government has a proactive responsibility to ensure that health care professionals are aware of the existing common-law situation and the importance of facilitating informed consent, especially through counselling and education. Any problems identified with existing common-law practice regarding young people's informed consent can be addressed through professional and popular education.

The recommendations from my preceding remarks are these: Section 8 should be amended to delete any reference to a specific age as a determinant of capacity to make decision on treatment. The interests of both young people and society as a whole are best served by relying on existing common-law practice.

The second recommendation is that the provincial government should support and fund education to health care professionals and to the public about the application of common law to young people seeking confidential treatment.

Another concern that we have is that under the proposed legislation, treatment is defined as "anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose, and includes a course of treatment." In our opinion, the definition could include general health teaching, counselling and public health screening programs.

The lack of clarity in Bill 109 about what constitutes treatment could seriously affect the delivery of school health programs which focus on general health teaching and counselling. Public health teaching on sexual and reproductive health begins at very early grade levels within the school system. Ministry of Health mandatory program guidelines endorse such programming. These programs provide information that promotes positive health behaviours and practices and empowers individuals to participate in health care decisions. The ultimate goal is to prevent long-term negative health consequences. Students have followed up with individual counselling and are often referred to other counselling and health services.

A recent Ontario study found that fewer Ontario teens were getting pregnant and that the abortion rate among adolescents may also be on the decline. The authors attributed this to the provincially funded pregnancy prevention programs. This was written prior to the article in the *Star* yesterday, which some of you may have seen, which said that teen pregnancies are down and gave credit to public health and education services for this. We wish that this would continue.

Prevention strategies of providing health education and counselling, which are critical to empowering individuals to participate in health care decisions, must not be jeopardized by making the definition of "treatment" so broad that they are included. So our recommendation 3 is that the definition of "treatment" be rewritten so that it specifically excludes the provision of health teaching, counselling and public health screening programs.

Finally, regarding the composition of the review board, the members of the Consent and Capacity Review Board are to be appointed by the Lieutenant Governor in Council; there are no criteria for the selection of board members except in cases dealing with capacity. We believe that members of the board must be broadly representative of the social, cultural and ethnic diversity of the province. More specifically, guidelines must be developed so that at least one member of a panel has expertise within the treatment area concerned.

We have two more recommendations: (4) that the board have representation from a wide range of social, cultural, ethnic and professional backgrounds, reflecting a diversity of perspectives on the issues to be reviewed; (5) that guidelines be developed for the selection of board members and the operation of the board so that at least one member of a panel has expertise in the treatment area under consideration. That completes my comments.

**The Chair:** Thank you. Each caucus will have about six minutes for questions and comments.

**Mrs Sullivan:** I think that this is an extremely useful brief. We have had some earlier discussion in committee, including when the Minister of Health attended the sessions of committee, in relationship to the questions surrounding age. I think the arguments you have put forward here really articulate the issues that have to be dealt with on age questions. The concept of "mature minor" is one that we feel has to be explored further in terms of the legislation. We are very supportive of all of the points that you have raised here.

The one area that I wanted to explore further with you, because it may mean that ultimately there will have to be changes in other legislation, relates to the age sections in the Child and Family Services Act. For children who are in care, children who are also victims of sexual attack, the consent requirements there are indeed quite different, and there is an age factor involved. I wonder if you could, as an adjunct to your brief today, speak to the Child and Family Services Act, and if you see concurrent changes required there.

**Ms Bean:** I am not really familiar with it, I am sorry. So I do not feel competent to respond to your question. I wish I could.

**Mrs Sullivan:** Okay, we will leave it at that. In that case, I would ask that the parliamentary assistant undertake to explore also the provisions relating to consent to treatment in the Child and Family Services Act as they would apply to this act as we move through this system. I think these are urgent and important questions.

**Mr J. Wilson:** We have tried to deal with two of the major points that you concentrate on in your presentation through amendments we have already introduced. Have you had an opportunity to review those amendments?

**Ms Bean:** I have not, I am sorry.

**Mr J. Wilson:** We will ensure that the clerk provides you with a copy. One is a definition of "treatment" which, I think, deals with your concerns. Also we have removed the reference to age in the capacity for consent section. Again, thank you for reiterating that. I hope, once you have had a chance to review these, that perhaps you will agree with the changes we have made and help us convince the government to do so.

1120

**Ms Bean:** There was a problem with our fax machine yesterday. I did hear them over the phone and wrote them down, and I seem to be in general agreement with them, but I would like to see them written.

**Mr J. Wilson:** We will ensure you get a copy.

**The Chair:** I would like to mention that you have them beside you now. The clerk has just delivered them. Further questions or comments? Seeing no further questions or comments, Ms Bean, on behalf of this committee I would like to thank you for taking the time out this morning and giving us your presentation this morning.

**Mrs Sullivan:** On a point of order, Mr Chairman: I wonder if Mr Wessinger would like to discuss the question of age a bit further, because the minister did speak to that in her first session, and I think it is important that it be put on the table in the context of what the government intends to do with amendments in this area, and additionally, when health practitioners can indeed expect to see, so that they can comment on, the minister's actual intentions here.

**The Chair:** That is not a point of order, but if Mr Wessinger would like to respond, he may.

**Mr Wessinger:** I will not speak for the minister, but I will be happy to make some comments as a member of the committee and as an individual member and just say that I think every presentation we have heard has been quite unanimous with respect to the matter of addressing the question of the age, and certainly the presentations have been persuasive in that matter.

**Mr Sterling:** If this committee would agree to go into clause-by-clause, we are quite willing to put forward all our amendments and deal with this right at this point.

**The Chair:** I believe that will be held over until after the consultations are finished.

**Mr Sterling:** Why not deal with it now? The government has said that it agrees. Let's get on with it so we do not have to have other groups come in and reiterate the same point.

**Mr Winninger:** We need a French translation.

**Mr J. Wilson:** Pas de problème.

**The Chair:** Order, please. Do we have unanimous consent to proceed to clause-by-clause? No, we do not.

#### SCHEDULING OF PRESENTERS

**Mr Winninger:** I feel it incumbent to revisit another issue, and that is the issue surrounding what was one witness who wished to attend here, who presently resides in Kingston, and now I understand there is a second witness, who is in Mimico, who may be in similar circumstances. Let me just recap my understanding to date and then perhaps we can decide where we want to go from here.

With regard to the witness in Kingston, who has been offered video conferencing and declined, who has been offered the opportunity to submit a written paper and declined, either directly or through his counsel, and who now finds that the medical facility in which he finds himself declines to have him attend even after we have agreed to pay the cost of security guards to accompany him here, I understand it may be helpful to the facility if the committee were to call and say, "Yes, we are interested in having him come, notwithstanding your objection." It may be that the facility is willing to secure the necessary people to accompany him down here.

I think that the case to be made is strengthened in that there is now a second individual who was on the standby list—correct me if I am wrong—to speak to this committee, who also wishes to come and that we should, as a committee I would move, ask either our Chair or our clerk to call these two facilities and indicate our strong interest in having these witnesses attend, because otherwise they do not seem to be given the same choices that other people who are not in these facilities enjoy.

We can look at the letter of the law or we can look at the spirit of the law, and here I am adverting to the spirit of the law, which is that this committee should be receptive, no matter what people have to say, to their opportunity to give evidence. If a health facility, due to its own internal considerations, is at this time declining to allow the individual to come, we should indicate a strong preference that those individuals be allowed to give evidence and not just say, "Well, we're giving you the same rights other witnesses have."

**The Chair:** So you move that the clerk calls the facility and indicates the committee's strong interest in having these individuals attend?

**Mr Winninger:** Yes.

**The Chair:** Okay. Ms Sullivan.

**Mrs Sullivan:** We did speak to this to a certain extent two days ago, and of course the subcommittee has met. It is very clear that the one institution in particular, although I am less certain about the circumstances at the second, is unwilling, without the force of a Speaker's warrant, to allow that person to testify before this committee. If the

government members are indeed committed to allowing a voice to and the autonomy of vulnerable people, and this person has clearly been identified through the words of the parliamentary assistant in a sensitive way as being a vulnerable person, then surely the actions should not be simply to express an intent. Are the government members indeed willing to ask for a Speaker's warrant? The government members have the majority vote on this committee; let's not forget that. Are they willing to act and insist that this individual be here and able to testify in person?

There are not many days left for public hearings. It seems to me that another phone call, given that there have been other phone calls, may not be as satisfactory as the parliamentary assistant indicates he hopes the outcome will be.

**The Chair:** Just for the information of the committee, if we decide to go with the Speaker's warrant, we would have to wait until the House is called back and it would have to be debated in the House.

Also for the information of the committee, this has been discussed. The point is that these people have been invited to come and give their presentations. We have not intervened on anybody else's behalf to come in to give their presentations, and the option has been made available that they could give written submissions. They have chosen not to do that, just for your information.

**Mr Winninger:** I will respond after Mr Wilson.

**Mr J. Wilson:** I would just briefly say to Mr Winninger that it would seem to me that now that we have a second request, that does not strengthen the case. That would dilute the case, I would think. It is almost as if the floodgates are opening and people are wanting to appear before this committee. While they may have a right to do so, it does not seem they are very practical in that we have already extended a number of ways in which they can communicate with this committee. I feel the committee has been extremely reasonable in this case, and perhaps if the government brought forward its amendments, neither individual would have to appear.

**Mr Winninger:** Could I respond briefly?

**The Chair:** After Ms Akande.

**Ms Akande:** It is your discussion, David, so I will defer to you and then perhaps my comments will add to yours. Go ahead.

**Mr Winninger:** Thank you. I will just respond to Mr Wilson's point first. I do not think it dilutes the strength of the motion, in that our list of deputations and our standby list are now finite, as I understand it. Both of these individuals were either on call or on the speakers' list. We are not aware of any other such individuals who want to come before the committee and who face these peculiar obstacles to their attending. That is all I have to say in response to your point.

1130

In response to Ms Sullivan's point, it is not my understanding, from informal discussions with the clerk or the Chair, that these hospitals are saying the only way they will send these people is with a Speaker's warrant. I think

my motion is a very reasonable one to make under these circumstances, so that we can say we did not leave any doors unopened or stones unturned in order to make every reasonable effort to have these people attend. If, as I understand it, these facilities may be awaiting a call from this committee indicating a strong preference that these witnesses be allowed to attend, given that we have agreed to pay their costs of coming here, I do not think that is an unreasonable motion to make.

**Mr J. Wilson:** On that point, as an attendee at the subcommittee meeting, I agreed with the invitation that had been extended to the one gentleman, for himself only, to attend. Subsequently, we have been told that the hospital would have to send a couple of employees with that individual. I personally would not be in favour of the expenses incurred there. Also, two people of the hospital staff must also take the day off to accompany this person for the day to attend here, take time out of work they could otherwise be doing, and I think the committee has been most reasonable in its offers to date.

**The Chair:** To clarify that, Mr Wilson, the committee has already extended that we would pay for the two experts to come.

**Mr J. Wilson:** But I did not agree to that. I did not agree with that, and I was surprised to hear that at subcommittee because that was not discussed. That was automatically done, which cannot be done. It was automatically done before it was even brought to subcommittee, and I certainly did not agree with that.

**The Chair:** I have another point of clarification on the second request to come. It would take direct intervention on behalf of this committee to ask for a day pass, so just asking them to allow this witness to appear—

**Mr J. Wilson:** Let's be frank. The floodgates are opening; word is getting out. All the pious speeches in the world are wonderful, but the fact is that I think you as a government have a lot of serious things to do in this legislation, and your preoccupation with bringing people out of institutions here is—while it may be laudable, I think your priorities are a little backward.

**Ms Akande:** I think that the very issue that they can is an issue of advocacy, and it would seem inappropriate to me not to do everything possible to have those who are most concerned with the issue able to come to this committee and to present their remarks in a way in which they feel comfortable. In spite of the fact that alternative ways have been offered to people to present their remarks, it is not necessarily comfortable or comforting to those who have to use this system. Others have had the benefit of coming and presenting to us, and I think that in this particular instance it would really speak almost negatively to the very thing we have dedicated ourselves to, the very interests and the very goals of this, not to have those people be able to come.

I would support Mr Winninger's motion, and the only concern I have about it is that it may in fact not be strong enough and there may be greater measures necessary.

**The Chair:** First-time speakers. Mr Sterling.

**Mr Sterling:** This individual obviously is incarcerated in some way. I do not know whether it is under the Mental Health Act, whether he is—

**The Chair:** Under a Lieutenant Governor's warrant.

**Mr J. Wilson:** Both individuals?

**The Chair:** No, just the one, the first one.

**Mr J. Wilson:** What about the second one? Why does he need a day pass?

**The Chair:** We were informed that he needed a day pass.

**Mr Sterling:** He is under a Lieutenant Governor's warrant. I cannot judge what the person is there for; I am not given that information. I feel very reluctant to ask an institution to allow this individual to come out of that institution. I feel very reluctant to incur the cost, which would amount to \$1,000 to \$2,000, without knowing whether this person is sane or insane. If in fact he is insane, how does this committee justify the expenditure of \$1,000 to \$2,000 to call before this committee an insane person? How do you justify that when we do not have enough food for our food banks? How do you justify that? You have to extend an arm as far as you can, or an invitation as far as you can, but come on, let's get with it. Are we going to go to the ridiculous here?

**Mrs Sullivan:** I know that Mr Wilson had difficulty with the question of the institution's workers appearing with the individual in question. Assuming that the individual in question does come, our party would consider those workers as attendant care people and we would see it appropriate that the committee pay for their attendance here. However, once again, I think that the emphasis and the clear direction of the intent must come from the government members.

**Mr J. Wilson:** I think there would be a number of groups out there who feel we have just stretched the definition of what is meant by attendant care in 1992. I fall back on my earlier comments, and what Mr Sterling has also said, that without further information it is, in all seriousness, difficult to make a decision here. If we are not able to have full information, then once again we are spending time today debating this. Mr Chairman, I would ask you why is it that we cannot get full information on this?

**The Chair:** Nobody has asked for the information yet. What information would you like, exactly?

**Mr J. Wilson:** I think Mr Sterling raises a good point. What is the mental state of these individuals? Why are they where they are? I understand there are privacy provisions and considerations, but perhaps the individuals themselves would like to volunteer that information.

**Mr Winninger:** I would just raise as concerns the protection of privacy and the relevancy to what they have to say on these bills.

**Mr Sterling:** The relevancy is, do we have anybody who is talking with any kind of sense in front of the committee?

**Mr Winninger:** I think my experience has shown it is in the mind of the beholder.

**Mr J. Wilson:** I find it philosophical, because we are adding—

**Mr Sterling:** The state has said that he is not sane, if he is under the Lieutenant Governor's warrant.

**Mr Winninger:** He could have been incompetent to—

**The Chair:** Order, please. It is my understanding that the second presenter wants to come and talk on death in the prison system.

**Mr Malkowski:** We are asking for a very simple thing. We have said we respect the rights of all individuals to come and present here. I do not think it is worth arguing over a way to prevent this from happening. We should respect the democratic process, and that is giving this man this opportunity. I do not think we are asking for something outlandish.

**Mr Sterling:** Over the 15 years that I have been a member of this Legislature, we have denied thousands and thousands of witnesses the right to come in front of committees because we have not been willing to pay for witnesses to travel from Ottawa—from my riding, the Ottawa area—to Queen's Park in order to make their designation. We have asked them and said, "You have the right to make your presentation in writing, if you so choose."

In this case, we have not only offered the witness that opportunity but we have also offered another opportunity to connect him here by electronic input. I have no problem with asking, because we have some responsibility to be fiscally responsible as legislators, what we are going to get in terms of input for our money. That is why I asked before that we have some kind of preliminary review. Ask them to send in a written brief and if we think that in fact it has some great revelation to us, then we might consider that as a second step.

This individual has chosen not to respond in any way. I take great objection to spending something like \$1,000 or \$2,000 to bring this individual here when we have denied thousands and thousands of other witnesses the right to come in front of this committee, without any proof that

this individual is going to shed any light on this legislation at all.

**Mr Winninger:** Mr Chairman, I am willing to have my motion deferred until later today so that we can have some discussion.

**The Chair:** Until later today? I think we should get this settled once and for all today. Just for your information, the original subcommittee that approved the funding was Mr Harnick, Mr Morrow and Mr Chiarelli. That was the subcommittee that approved the funding to bring the witness down, with escorts.

**Interjection:** It must have been prior to hearings.

**Mr Sterling:** We withdraw from that approval and I would ask that any motion to bring these forward have that as their motion—that they pay for this individual and the guards or whatever is necessary to bring this person here.

**Mr Malkowski:** Possibly, we should then at this point recess and have the opportunity to discuss for 10 minutes and come back on it.

**Mr Marchese:** Mr Chairman, there's a motion to defer.

**Mr Winninger:** I am asking that my motion be deferred until this afternoon and then the Conservative caucus can discuss its position.

**The Chair:** Is there unanimous consent to defer?

**Mr J. Wilson:** No.

Interjections.

**The Chair:** All those in favour of a 10-minute recess to discuss this?

**Mr Winninger:** I am asking that it be deferred until this afternoon's sitting.

**The Chair:** You did not get unanimous consent on that.

**Mr Winninger:** Fine. I will withdraw my motion and return it this afternoon, if you like.

**The Chair:** Fine. Seeing no further business before this committee this morning, we will recess until 1:30 this afternoon.

The committee recessed at 1142.

## AFTERNOON SITTING

The committee resumed at 1347.

CANADIAN ASSOCIATION  
FOR COMMUNITY LIVING

**The Chair:** I call this committee back to order. I would like to call on our first presenters, from the Canadian Association for Community Living. Good afternoon. As you know, you will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow questions and comments from each of the caucuses. As soon as you are comfortable, please identify yourself for the record and then proceed.

**Ms Richler:** I am Diane Richler. I am the executive vice-president of the Canadian Association for Community Living. With me today is Dulcie McCallum, who is our consultant on government and legal affairs.

I would like to thank you for the opportunity of presenting to you today and to mention that it is quite unusual for us as a national organization to seek to make representation to a committee of a provincial government. One observation is that we are much more used to making presentations in Ottawa, and the turnout of committee members to whom we have presented there is far inferior to what we see here today, so we are very happy to see the level of interest on the part of this committee.

**Mr Poirier:** So you will come back.

**Ms Richler:** The reason we wanted to appear before you today is that the issues before your committee are of great concern to our association across the country, and the related issues of supported decision-making, approaches to consideration of substitute decision-making and advocacy are being discussed by our members from across Canada right now. We have a task force that is looking at the issues that includes representation of self-advocates, individuals who have been labelled mentally handicapped who are speaking on their own, parents of sons and daughters who have been labelled mentally handicapped, lawyers and other concerned citizens, so we are here today to share with you some of the concerns and experiences that have been raised by our membership from across the country.

I would like to mention as a preface to our remarks that we fully support the presentation made to you by the Ontario Association for Community Living, which is a member of our federation. I also want to draw to your attention, however, the brief that was made by the Canadian Coalition for the Prevention of Developmental Disabilities on February 20. As a member of that coalition, our name is included in the brief that was presented. While we are a member of the coalition, we had not seen the brief that was presented to you, had never endorsed it, and do not endorse it. So on the record, I would like to have that straight.

The Canadian Association for Community Living is a national advocacy organization which is a federation of 10 provincial and two territorial associations. Many of you may have known us before 1985 when we were known as the Canadian Association for the Mentally Retarded. It was

when people who themselves had been labelled started to speak out and convinced us that we had to change our name that we did so. In speaking out, they helped us to realize that our task was not to try to improve the individuals who had been labelled, or even to support people, but rather to help communities to include people who had been labelled in all aspects of community life.

Our concern in being here today is that many traditional approaches to supporting people, such as guardianship, in fact replace a person's right to make his or her decisions in life. They lead to systems in which there is no reason to try to discover that person's own choices, thoughts or feelings. In accepting that someone else will be permanently responsible for making choices for the person, we discourage the creative drive which leads to attempts to unlock the expression and communication of labelled people.

I will draw your attention to an issue of a magazine we publish, called *Entourage*, that is in your package. One article by Justin Clark, whom many of you may have met, talks about the impact that people viewing an individual as vulnerable can have on that person's life.

We were extremely impressed by the approach in Ontario which sought to bring in a comprehensive package of legislation, particularly a mechanism for advocacy which would provide support for the thousands of Ontario citizens who are vulnerable because of where they live and because they have no one to support them. However, we are very concerned that the concept of advocacy and the creation of an advocacy mechanism would address only a piece of the puzzle and that the other important concerns that have to be addressed in terms of changing the kinds of supports and services available to people are not addressed. To our mind, it is like giving somebody a warranty without giving him the goods or product.

With regard some of the examples that I have heard of in Ontario in the last couple of weeks of people living in institutions who cannot get out, what they need is not a regular visit or the capability of someone to come in any time of the day or night to see how they are doing; what they need is to get out of that institution. Similarly, people who are living with parents who are aging and have concerns about what the future of their sons and daughters is going to be are being told, as recently as the last couple of weeks, that schedule 1 facilities are the only, and the least restrictive, alternative available to them. Our concern is that what those people need is not someone to say that where they are is bad but the supports that are going to help them participate in the community.

Dulcie McCallum has been working with our provincial and territorial associations across the country and I would like to turn to her to make some more comprehensive comments.

**Ms McCallum:** I bring a perspective that enjoys the privilege of having been involved in a number of jurisdictions looking at this same question, albeit the processes in every area are different. The Yukon is looking at guardianship, and I

personally was involved in preparing the report for that government. British Columbia has undertaken a comprehensive community consultation that has been ongoing now for over two years. In Saskatchewan the public trustee has even hinted that she is prepared to look at the question of guardianship and the Dependents' Relief Act together. Manitoba is undergoing a review of that portion of its Mental Health Act that deals with mentally retarded people and makes provision for guardianship. New Brunswick has an older parents' project which is, for three years, looking at all aspects of issues concerning older parents, including guardianship. Newfoundland has just been invited by the Minister of Justice to undertake some community consultation on this question as well.

Through my involvement in all of those regions, I can say that my remarks today try to see this as an analysis of where we have come from yesterday, that we are at a crossroads to make some progress and what our eventual model might look like.

I think it is safe to say that our legal history, our legislative history and our government are designed on what I call three Ps, and those are property, privilege and power. Unfortunately, the guardianship model that is presently on the table here in Ontario to some extent continues to perpetuate those elements as appropriate foundations upon which to base a law regarding people labelled incompetent or incapable. It has historically been the case that it is a concern for the state to preserve property. It was the foundation of common law inevitably to treat some citizens as being less privileged, prisoners being an appropriate example, and to exert power over individuals who have been labelled or discredited.

Today we have an opportunity to make progress, and I suggest to you we actually have a commitment to make progress. It is based in part on the patriation of the charter and particularly the equality rights provision. This has imposed an obligation on you as a government, and we as a community, to ensure that there is equal access, equal benefit of the law, regardless of disability. I suggest that the notion of capacity and competence as it presently exists in these pieces of legislation does just that—makes a distinction based on disability.

It is no longer acceptable for antiquated concepts to be used against people whose capacity is challenged. That includes all of us here; we will all age. With people, because of their level of literacy, disability or illness, competence in itself is not a helpful concept and indeed has been shown not to be very determinable. It has never been able to be assessed very clearly. In fact, it is riddled with elitist, racist, ageist, sexist and ablest overtones. We need to abandon competence if it means to have a rational state of mind and independent thought.

Included in your package are a number of principles we suggest should guide you in your deliberations. These speak of commonality and interdependence.

The effects of guardianship are overwhelming. It is not merely a question that a court order is obtained and justice is served. For the most part, any substitute decision-making order totally disfranchises the citizen. The legislation is not in the result single-purpose. The guardianship declara-

tion is referentially incorporated into other laws with devastating results. It may mean the person can be sterilized, institutionalized, denied the right to marry or parent, lose economic opportunities, such as the right to contract, and denied the right to vote. Indeed, in subsection 2(4) of the Substitute Decisions Act, contracting is excluded for people who have a guardian.

The new Canada Elections Act just proposed by the Royal Commission on Electoral Reform will mean that anyone who falls under your guardianship act, the Substitute Decisions Act—and I would suggest to you, partial or full—will not be able to vote. That is because the section of the proposed act reads: "Every person has a right to vote in an election unless that person is subject to a regime established to protect the person or the person's property pursuant to the law of a province or territory because the person is incapable of understanding the nature and appreciating the consequences of the person's act."

In its report, the royal commission refers to "totally incapable." Unfortunately, in the draft act the word "totally" is removed: No decision, a bad decision, an imprudent decision, a horrible decision. Many people in our community, not the least of whom are men who violate women, people who violate children, rich people who gamble away their savings, these people may make bad decisions, but it is not likely that someone is going to intervene. It is often not the quality of the decision that gives rise to a guardianship order; it is the person and the category in which they fall.

In Ontario, the Ministry of Community and Social Services has recently issued a prevention policy framework in another area, related to children. But the language of those values is critical: "To enable individuals to assume responsibility for themselves and to foster self-determination, promote self-reliance and empowerment, support and strengthen family life while remaining sensitive to the needs of individuals, groups and communities at risk, respect the principle that prevention focus on the dynamic interdependence of individuals and their environments."

Also, in a public consultation that the ministry undertook in relation to seniors and support services, I quote again: "People who receive long-term care and support services do not want to sacrifice their individuality or dignity, and they want to participate in determining what services they require and how they are provided." People who are subjected to guardianship, be they people with mental handicaps, people who are mentally ill or seniors, all fall to the same fate.

1400

People are not vulnerable because they have a disability or because they are old; people are vulnerable because of what we as a society, as a legal system and as a community do to them. People are institutionalized, neglected, denied access to services and facilities, excluded into segregated and parallel systems and denied an active so-called voice in community affairs. It disengages people from their communities in two ways. The first is that it puts the individual in need of support at arm's length from government. The guardian is the person who assumes care and control, taking responsibility. So if the person, despite the

fact that they have a guardian, is placed at risk, the government is off the hook.

The second way is that people are denied full participation in that those decisions which are not transferable to a guardian, such as the ability to make a will, the ability to initiate divorce proceedings, are totally lost to the person. So either they give them away or have them taken away and given to a guardian or they do not have the right to exercise them.

Governments must not relinquish their responsibility to the vulnerable citizens, as they are called here, be they seniors, new Canadians or mentally handicapped. Disguising the law with rhetoric that is a protection mechanism for so-called vulnerable people will not work. What can the three Ps for tomorrow be? I suggest to you that they are: participation, provision and protection. It is incumbent on us to design mechanisms that will enhance people's opportunity to participate with supports and services and to protect the so-called vulnerable citizens from abuse and risk. Everyone is entitled to participate to the best of their individual ability. In the wake of the charter and the interpretation given to the equality rights by the Supreme Court of Canada, any legislation regarding decision-making must enable, not disable, that participation.

The law must empower people and provide a means for improved inclusion. The historical disadvantage associated with being mentally handicapped has, in essence, been the lack of opportunity to be considered capable and contributing; this is the very disadvantage that the law must ameliorate. This remodelled decision-making process will recognize the role of people assisting people to decide, which is true for all of us. It will respect unique forms of communicating one's wishes, such as facilitative communication or Bliss symbolics. It requires that the safeguards are in place that will review decisions, not people, be they Nancy B. or Justin Clark.

Providing people with supports and services they want and require will reduce their vulnerability and improve the quality of their lives. Abuse and neglect are not to be tolerated. Guardianship does not protect people: Children with parents are abused; adults with guardians are abused. Mechanisms must be put in place that will eliminate the abuse and neglect of adults. In part, this is accomplished by having an infrastructure based on inclusion. Another part of the equation is having access to supports and services required. When those people supporting are given status and encouraged to be involved, integration improves and risk is reduced.

In addition, on an individual basis, an adult protection model can permit investigation and intervention. On a systemic basis, a means to investigate, to intervene and to advocate, as proposed under the advocacy system, for those who are at risk or who have no one is necessary to change systems and can be mandated by legislation. This form of systemic activism and improvement ought not to be confused with personal advocacy from supporting friends and family.

We have limited resources in this country and—it probably does not need to be said—in Ontario. We need to allocate and reallocate the limited resources very carefully.

We need social and legislative changes that mirror the political will to make major improvements for those who are devalued and excluded. We must not create a new system that introduces progressive, non-intrusive changes that permit the non-labelled privileged to be self-determining while the others are excluded.

A place to begin in reviewing the existing model would be to hold it up to the standards of an appropriate statement, of principles and I would suggest that as the legislation presently stands, it will not stand the test. A place to finish is when we have a ramp in place, whether it is a signer for a person who is deaf or a ramp for a person who has mobility impairment. We have ramps so they are included as full and participating members and citizens in our community. What we need for people with mental disabilities and seniors is a ramp, and the legislation should form the foundation for that ramp so they are fully included with us. We would be happy to answer questions.

**The Chair:** Thank you very much. We have about three minutes for each caucus. Mr Wilson.

**Mr J. Wilson:** Thank you very much. It is a very interesting brief. I am sorry, I have not had time to read it all. I kind of missed the most important points, which were your latter points dealing with the alternative model. Can you succinctly give me that again; you know, in lieu of guardianship?

**Ms McCallum:** In two words or less, the model would turn itself around. We recognize that some of us have informal support. You probably make decisions with your friends and family quite a lot. It is rare for us to make independent decisions. When persons are labelled, any effort they make to get support to make decisions is viewed or considered aberrant, in the same way as they may do something and I do the same something: with me it is a joke and with them it is deviant.

**Mr J. Wilson:** And unlike me, they have to declare who they consulted with on that.

**Ms McCallum:** Correct. You see, so long as there is a model in place that creates a distinction and takes away something from someone, those people will always be potentially subjected. For instance, a person who has gone to high school, has graduated and has a full-time job, happens to have Down's syndrome. Because the act speaks of people who are potentially candidates as incompetent or incapable, the provision in your new act that deals with the ability to enter into a contract places the onus on the person entering into the contract or receiving the gift to determine that that person was not incompetent or was not under a guardianship order.

People who have traditionally been devalued—very old people, people with mental handicaps—there will be a hesitation and a segregation and an exclusion of them. They will be disengaged economically because of the fear of that kind of provision. So whatever model you would have, it may be on a continuum of the amount of support, but you and I would fall under it. We would be able to make pre-declarations, but as the model moves forward it would all be based on support, empowering people, giving them status, rather than deciding that at some point along

the continuum we have to exclude a particular category of people.

**Mr J. Wilson:** Can I have one more quick question, Mr Chairman? Just in the area of guardianship, you have had extensive experience in this, I imagine, and I have not. Is it fairly easy to obtain a guardianship in this day and age where it exists?

**Ms McCallum:** I would say the answer to that is probably yes, certainly in—

**Mr J. Wilson:** That is the impression I got from your brief, certainly.

**Ms McCallum:** Yes. In British Columbia, I can say, when I was practising law, you could easily get a guardianship order based on two affidavits of two physicians. The person was usually served, but not necessarily—it could be waived—did not appear and there was rarely a trial.

**Mr J. Wilson:** So it was sort of an ex parte—

**Ms McCallum:** In fact, we had one client whose father got a guardianship order here in Ontario, and the young man was living in Vancouver, without notice and without presence.

To be fair, I think the old model was based on a medical model. It relied on doctors to have some expertise. I think that whole notion has been discredited. We recognize that is not what ability means any more and I think many of the medical community would join in that idea. So the fact that it was kind of a paper court order was certainly one of the reasons why BC initiated its consultation, because the provisions under the Patients' Property Act were so inadequate.

I would just add that I would not want to create a guardianship act that was incredibly fair, where we would have a huge, costly hearing and we would have lots of assessments, the person would be given notice and would come, and we would inject all these fairness techniques from section 7 of the charter, but at the end of the day we would be doing exactly the same thing to people: We would still be creating categories of people and taking things away. In a free and democratic society, where is the justifiable limit? If someone is incarcerated, is it okay that he cannot vote or is it okay that he cannot enter into a contract? Is that really appropriate for someone who is supposedly a full and contributing citizen? Are there other ways to allow them to engage in decision-making?

1410

**Ms Carter:** I will yield to Mr Winninger, and I will come in if there is time left.

**Mr Winninger:** Are there people living in your group homes who do not have friends or family outside the group homes?

**Ms Richler:** When you say "your group homes," the Canadian Association for Community Living does not operate any services. Are you thinking of group homes that might be operated by local associations for community living?

**Mr Winninger:** Yes.

**Ms Richler:** I would certainly expect that there are people living in group homes run by any agency that would be without family or friends.

**Mr Winninger:** Who would make decisions if people appear to be mentally incompetent to make those decisions on their own behalf in those situations? Do you know?

**Ms McCallum:** At present, I would say that oft-times service providers are placed in the untenable position of sometimes having to provide consent. But you make the very point, you see: those people who may be mentally incompetent. If we remove that concept from our minds and we recognize that some people need more support—in fact, in introducing this in the House, the minister said that the agenda is to create in Ontario a supportive environment where all people, including the most vulnerable among us, can meet their full potential with hope and dignity. That is absolutely right. Unfortunately, the acts do not do that, so in the guardianship situation where someone has no one, you build advocacy around him.

**Mr Winninger:** Sure. But just to come back to my original question, you say service providers sometimes provide consent. Where is the accountability there?

**Ms McCallum:** Absolutely. It should not be the case.

**Mr Winninger:** What should not be the case?

**Ms McCallum:** That people who are service providers should provide third-party consent.

**Mr Winninger:** Who else will there be if there are no friends and there is no family? Is it not better that the person who makes those so-called consensual decisions be someone who has the legal mantle of guardianship to make those decisions and is going to be accountable ultimately to the courts for how he or she discharges those obligations and responsibilities?

**Ms Richler:** If we go back to the situation of Justin Clark, he was a young man living in an institution who disagreed with his family, who ordinarily would have been the people to whom service providers would turn, and yet he was able to communicate well enough to the people working around him within the institution what his wishes were.

**Mr Winninger:** I have no argument, and that is why guardianship would have been contraindicated there, but I am talking about people who may not be capable of making those decisions. Do you agree with partial guardianship?

**Ms Richler:** No.

**Mr Winninger:** Why is that?

**Ms Richler:** We do not understand the concept of not being able to make decisions.

**Mr Winninger:** At all?

**Ms Richler:** That is right.

**Mr Winninger:** So what about these situations where service providers are making decisions? Why would they even need to if everyone, given supports, can make his own decisions?

**Ms McCallum:** Because no one will take their consent. I know physicians in Vancouver who will not deny any patient the opportunity to have the time spent with him

to get informed consent. Informed consent is an individual-based concept.

**Mr Winninger:** What if someone is in a coma? How do you deal with that?

**Ms McCallum:** It is a totally different situation. They may have made a pre-declaration by a health proxy or a power of attorney.

**Mr Winninger:** And if they have not?

**Ms McCallum:** If it is an emergency, nothing is necessary. One of the advantages of the model you have at present is that you have divided it up into pieces and you are addressing medical consent, which is a very critical point. There are issues for physicians, health professionals and for people needing access to medical services, no doubt about that, but that can be dealt with in the medical consent. If some provision needs to be made where no one has made a determination in advance and he is unconscious and it is not an emergency, then you may have some kind of mechanism of a list of who could step in as that person: his partner as defined by your act or his spouse, mother or father.

**Mr Winninger:** Are you not getting closer and closer to the concept of guardianship there?

**Ms McCallum:** Absolutely not.

**Mr Winninger:** Sorry; we have run out of time.

**The Chair:** Ms Richler and Ms McCallum, on behalf of this committee I would like to thank you for taking the time out this afternoon and coming and giving us your presentation.

#### ST JOSEPH'S HEALTH CENTRE, TORONTO

**The Chair:** I would like to call forward our next presenters, from the St Joseph's Health Centre, Toronto, ethics committee. Good afternoon. Just a reminder that you will be allowed a half-hour for your presentation. The committee would appreciate it if you could keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Sister Iredale:** The people who will present this afternoon from St Joseph's Health Centre are, in order of presentation, Sister Marcella Iredale, the speaker, Dr Doug Crowell, Ms Bridget Campion and Ms Catherine Cary.

Thank you for this opportunity to speak to this committee on the proposed new legislation. You have received written material, which we will speak to. Dr Crowell, Ms Campion and I will speak to themes which appear to run through the legislation. Ms Cary will propose a scenario which could become a reality should the legislation be passed in its present form.

St Joseph's Health Centre supports the principle which we understand the proposed legislation seeks to address and recognizes the importance of clarifying procedures for substitute decision-making. We are, however, concerned that although it is not the intent, the proposed legislation appears to ignore a basic principle which we believe to be

essential to all human interaction. That is respect for the dignity of the individual, of the human person.

In Bill 74 the person's right to privacy seems to be ignored. In the same bill confidentiality appears to be at risk, and in Bill 109, the autonomy, the right to self-determination, appears to be disregarded. We believe that the right to privacy, confidentiality and autonomy are inherent components of respect for the dignity of the individual. The proposed legislation appears to infringe upon this right in relation to vulnerable persons, whom the legislation proposes to protect, but also to others involved and affected in relationship with individuals.

Bill 74 infers that health care providers would not act in the best interests of patients, would in fact perhaps harm them. This inference is unjust, does a disservice to this group and thus ignores their right to the respect due the human person. Bill 109 would appear to treat the relatives of vulnerable persons equally disrespectfully by excluding them from participation as substitute decision-makers. Bill 110, in its amendment to the Education Act, treats parents and guardians in the same manner. Although it is not the intent of this legislation to disregard this very basic value of respect for the dignity of the individual, in its present form it would appear to do so.

1420

**Dr Crowell:** Thank you, Mr Chairman, for the opportunity to speak. I am Doug Crowell, the chief of anaesthesia and chairman of the hospital ethics committee. I have been a certified specialist in anaesthesia since 1962. Many of you will have already experienced the very personal feelings and worries that are associated with this trip into risks and life-and-death apprehensions. I would ask you now whether you think that perhaps your anaesthetist acted as an advocate for you—that is, acted in your best interests.

I am very puzzled by what appears to me to be a new perception: that I and other members of the healing professions no longer function in that role of an advocate.

Our institution at present has about 385 active treatment beds. Of that population, we can conservatively predict that at any time some 10% of patients would be classified as being incompetent. Also it is not unlikely that some 15 to 20 physicians could be involved in their care; that is, they are responsible for the outcome of their hospitalization.

I would ask you to ponder how the staff of the public guardian and trustee office will cope with the proposed advocate interviews relating to the patient's rights, arrange and hold the subsequent hearings dealing with competency, appoint an assessor, generate feedback to the care givers, review the history and course in hospital so as to understand the patient's condition, meet with the physician responsible, and then objectively be in a position to recommend a course of action, all of which may set aside the patient's wishes, even if they have been indicated by a previous directive, negate prior involvement of the family and do away with any vestige of patient confidentiality.

You will no doubt respond that most of this can be avoided by the prior appointment of a party who will have

power of attorney for personal care. We are concerned that even this can be refused by the public guardian or in some circumstances rendered null and void under this proposed legislation, and we assume that in order for this to occur there will have to be some sort of feedback to the public guardian. I would ask you: How much feedback, how often and by whom? Many clinical situations require hourly changes in protocol, some of which can impact upon patients' survival or indicate that further therapy is going to be of no benefit to the patient.

I would therefore ask you: Will all these changes in the direction of care require consultation with the advocate or his or her superior? Will every advocate or assessor decision be made in the patient's best interests? What will be their interpretation of what "best interests" implies?

Will this mean that life will be prolonged at all costs, or will we be effectively prolonging the suffering and the dying process against overwhelming odds, especially at this time now when availability of acute care beds is being eroded and there is little support for the concept of medical necessity in the eyes of both the law and the government?

Who is going to accept the legal responsibility that can arise out of unfortunate incidents or decisions? Will hospitals and physicians be relieved of this burden as long as they are being guided by the advocates and assessors? An ethical physician will not abandon a patient, but what actions will be open for the physician if there is not an agreement on the proposed treatment? Will there be an appeal process and, if so, how quickly do you think this will likely be resolved? For example, in November 1991 we had an incompetent patient admitted to the emergency unit for care. Two and a half months later, permission came from the public guardian and trustee office allowing this patient to have his surgery.

In addition, there are a number of issues which are legal in the eyes of the law but yet are repugnant to segments of society on personal, religious, moral or ethical grounds. The intrusion of advocates and assessors into the decision-making, not knowing where they come from, what religious doctrine or philosophy of values they espouse, appears to me to be a very unwelcome and invasive stranger at the bedside.

I am curious as to what has gone wrong with our society. What has happened that the elected representatives of the people are proposing these sweeping changes? Is there a perception that society fears it will not receive enough proper care or receive maybe too much care, as in Quinlan and Nancy B.?

As a taxpayer I have some concern that the present government policy with respect to health care funding appears to be eroding one's access to that care. This is not on the agenda today. However, the second issue certainly is. We feel that the proposed legislation does little to solve the medical-legal interface in coming to grips with the issues surrounding continuing burdensome treatment or therapy and substitute decision-making when there is little, if any, chance of ever improving the quality of life.

**Ms Champion:** My name is Bridget Champion. I work as a clinical ethicist, and as you can see, I am not going to speak to any practical points because of that. Instead, what

I would like to do is make one or two comments about advocacy, because it seems to me that advocacy is a major concept anchoring much of this legislation.

In the proposed legislation, the government is responding to a need, the need that somehow vulnerable persons are at risk in our society and, more specifically, at risk in health care. I do not have access to the government's studies, so I cannot say exactly how or to what extent vulnerable persons are at risk, but I certainly know that the perception of risk exists. For instance, in long-term care, which is an area of particular interest to me, people sometimes describe the relationship that exists between health care worker and health care receiver as custodial, and this indicates an imbalance of power. People sometimes talk about warehousing patients and residents, which indicates an objectification of them. We do know that our geriatric population in Canada spends a disproportionate amount of time in physical restraints.

In long-term care, many patients have difficulties expressing their wants and needs. Perhaps it would be more accurate to say that they do indeed express their wants and needs, but we have a difficult time understanding exactly what it is they are saying to us. Many patients in this population are deemed not competent, so it would seem that if an advocate were to be a real asset, it would be in a setting something like this. But is this the case?

My fear is that while vulnerable persons may be at risk, we will not through advocacy be diminishing that risk, because we will not be attending to the root of the problem. I believe the root of the problem is to be found in the relationship that exists between health care giver and health care receiver. This is a relationship which is often viewed as polarized, at the very least. Some people would even call it adversarial. To round out the picture, let me suggest to you that health care workers in long-term care are themselves at risk of verbal and physical abuse from patients and residents, and often suffer from low self-esteem.

My fear is that advocacy as it is being proposed—and by that I mean it is an automatic mechanism in certain instances—will deepen any mistrust that exists between health care giver and health care receiver. It will certainly make explicit any potentially adversarial nature of the relationship, because it simply shores up one side of that relationship. To me, the problem is that the presumption behind advocacy is that the relationship is one of power.

To me, the solution lies in building relationships of trust between health care receiver and health care worker, and this means attending to systemic problems. It means, for instance, changing our perceptions of vulnerable persons and working towards a model of mutuality; that is, realizing that health care workers and health care receivers engage each other in healing. It means making clear to staff in long-term care that what they are doing is worth while. It means realizing that healing and care in long-term care depend not so much on treatment as on establishing and sustaining relationships and human contact; that is, having the patient or resident seek and know that someone is truly listening. Sometimes it means merely keeping watch with a patient.

To me, this is intensive care in a very different sense, and yet we do not see it that way. But we are trying to. I would like to say that the long-term care and geriatrics mission statement, at St Joseph's Health Centre anyway, is based on concepts like these. It is by building relationships of trust that we will be able to lessen the risk at which health care receivers and workers are placed.

I believe the government is correct in identifying the need, but I am afraid that unless we attend to the systemic problems in advocacy, we will have proposed a solution that does not solve the problem.

1430

**Ms Cary:** My name is Catherine Cary. I am the unit administrator of the ICU-CCU, the intensive care unit and the cardiac care unit, at St Joseph's Health Centre, and I am the practical one.

It is 2 o'clock in the morning in the ICU on May 14, 1993. The telephone rings at the nurses' station. It is emerg: "Hi. It's Sue from emerg. We've got a patient, Mr Stanley Kowalski, down here for you. He is a 68-year-old Polish gentleman, a patient of Dr X. It looks like he's pre-respiratory arrest.  $pO_2$  in his boots and  $pCO_2$  is 73. He's acidotic with a pH of 7.22. Very short of breath and diaphoretic. He'll probably need intubation soon. His wife's with him. She speaks English, he doesn't. When can you take him?"

"Send him up."

This is an aside. How do these acts impact on what goes on in emergency? How does the patient get up to ICU? I am not sure.

The patient is admitted to the ICU. We recognize that he was a patient in our unit last year. His wife is in attendance. She is anxious and concerned. The health care team members conduct a patient assessment: central nervous system, cardiovascular system, respiratory, renal, metabolic. The diagnosis from emerg is confirmed. The assessment reveals also that Mr Kowalski is responding appropriately, but is becoming obtunded, ie, he is becoming incapacitated. The health care team discusses and debates the options. Someone says, "I wish we had an algorithm to sort this out."

Option A:

The health care team: "One option is the SDA, the Substitute Decisions Act. We are generally supposed to use that with people who have chronic illness, but he was here last year with the same thing, and it may become a chronic problem. All right, let's go with that.

"Mrs Kowalski, in order to ensure that your husband's rights and wellbeing are protected, we are going to call in a government-appointed advocate. This person will come and explain what is going on to your husband. He will not leave until he is satisfied that he has done the best he can in providing this explanation. We will request that he be able to speak Polish."

Mrs Kowalski: "Why? I always interpret for my husband. Last year, was I wrong? Did I do something wrong? What will the advocate tell my husband that I can't? How will he know what to tell him? My husband is sick. Can he come now, at 2 o'clock in the morning? How long will he

take to get here? All right," reluctantly, "call him, but please, my husband is so sick."

Option B:

The health care team: "Maybe the better option is the Act respecting Consent to Treatment. This could quite conceivably be considered an acute illness and incapacitation, temporary in nature. Let's go with that. The patient is now obtunded, so we'll have to speak to his wife.

"Mrs Kowalski, has your husband appointed you to be his power of attorney for personal care? If so, do you have any documents to prove this?"

Mrs Kowalski: "I don't understand you." An explanation is given. "Well, no, but I am his wife. I help him. He is my husband, I love him. I listen to you, doctor, and then I tell my husband, like last year. He is sick, doctor."

Doctor: "No, I'm sorry, Mrs Kowalski, we can't do that now. There is new legislation to protect the rights of your husband. There is a formal procedure to follow. We must consult with these people in this order: advocate, guardian, representative from the boards, spouse and so on."

Mrs Kowalski: "But I am number four on the list. Why? Why am I on the list if I am number four?" She is very upset. "My husband is very sick."

Option C:

The health care team: "Surely this situation represents emergent care. We can certainly show that without intervention in the next 12 hours Mr Kowalski's condition will deteriorate significantly.

"That's all right, Mrs Kowalski. We're going to look after your husband. This is what we propose to do. Do you think this is what your husband would want us to do?"

Mrs Kowalski: "Oh, thank you. I trust you, doctor. Help my husband. Thank you."

Care is provided. The nurse reminds the physician that documentation of care provided must be sent to the office of the public guardian and trustee. Arrangements are made to copy the chart and send it.

The telephone rings at the nurses' station. It is emerg.

**The Chair:** Thank you. Questions and comments? Each caucus has about three minutes.

**Mrs Sullivan:** I was particularly taken in your presentation by Ms Campion's statement on page 7, "The presumption behind advocacy is that the relationship is one of power." I recall another presentation from an advocacy organization that suggested that one of the problems with the Advocacy Act as presented was that the act provided to empower the advocate in fact more than it allowed empowerment of the patient. I thought that was quite an interesting response, and while that organization believed a new and different and more expensive approach to advocacy was important, they were also very concerned about the question of the power balance, patient versus advocate. Would you like to expand on that thought just a bit more for the committee?

**Ms Campion:** I guess in my mind's eye, the scenario I was imagining was just the sort of spiralling of advocates. As I have mentioned, nursing staff, for instance, are at risk in long-term care from patients and residents. So I

thought to myself, "Perhaps then they too would have to have advocates." I could not in my own mind imagine that, say, health care administrators would ever end up with advocates on their behalf, but I just saw that it was like an arms race, basically, and I was just afraid we were keeping the problem intact. It is an amazing idea to me that in health care the basic relationship is one of power, and I think we have to try to build it another way if we are going to solve the problem.

**Mrs Sullivan:** The other observation I want to make, because I know we only have three minutes per caucus, is that in Ms Cary's presentation, under option 1 of her scenario preliminaries, indeed the diagnosis could not have been done in the first place under this act.

**Ms Cary:** That is what we were wondering about.

**Mr Sterling:** I would like to ask the parliamentary assistant for the Ministry of Citizenship about the concerns of Dr Crowell with regard to the advocate. How is the advocate going to understand the religious beliefs, the beliefs of the family of the individual; how is he going to represent those interests in advising the incompetent patient?

**Ms Carter:** Mr Sterling, I do not think the advocate advises the patient, in a sense. They are—

**Mr Sterling:** I did not ask you; I asked the parliamentary assistant. Excuse me.

**Ms Carter:** Oh, I am sorry.

**Mr Malkowski:** I would refer this to Trudy Spinks.

**Ms Spinks:** I think that in the scenarios described by the presenters, the role of the advocate is a fairly straightforward one, as is described under the Consent to Treatment Act, to provide the information that the individual has been found to be incapable and has a right to appeal that decision. I do not think it involves the advocate in making judgement calls in presenting his or her views of the individual's best interests; it is an informational function.

**Mr Sterling:** Let's take the example, then, of a Jehovah's Witness who does not believe in taking a blood transfusion. The patient is a Jehovah's Witness. Does the advocate take that into consideration in his advice with regard to taking a transfusion?

**Ms Spinks:** The advocate would not be advising the individual whether or not to take a transfusion. The advocate is telling the individual that he has been found incapable, that someone else is proposed to make the decision on his behalf and that he has the right to challenge that finding.

**Mr Sterling:** If that is all the advocate is doing, I do not know why you have advocates. If that is the role of the advocate, why do you not just require every health practitioner to warn the person he should have that? Did you want to say something?

**Mr J. Wilson:** I think the point on that too then is, why in the act is the advocate having access to the clinical record? It would be of no use to the advocate.

1440

**Ms Spinks:** If I could just comment, I am addressing the scenarios that were presented by the presenters. I think they are talking about the role of the advocate with respect

to medical treatment decisions under the Consent to Treatment Act.

**Mr J. Wilson:** I think you were responding to our questions. Why does the advocate, if that is role of the advocate, need all these other sweeping powers, including the access to the medical record?

**Ms Spinks:** The advocate has other roles under the Advocacy Act, but the issues raised by the presenters concern the advocate's role, I believe, under the Consent to Treatment Act. If an advocate is in another capacity serving an individual who has preferences with respect to their religious beliefs and so forth, then obviously the advocate's job would be to represent those on behalf of the person to other individuals.

**Ms Carter:** I am addressing the role of the advocate under the Advocacy Act, which is to help the people who are vulnerable but not incompetent; in other words, they are capable of expressing their own opinions. The function of that advocate is simply to help the patient express his own wishes, so the values of the advocate would not be relevant because, as I say, they are just monitoring the patient's own wishes. The advocate would leave immediately if the person did not want him to be present, and he will preserve confidentiality, except in some very specific situations. I think, if you look through section 30 of the act, you will find that is quite tightly described.

At the top of page 8 you say, "Much of healing depends on being heard." Since that is all the advocate is doing—listening to the person's own opinions and trying to pass those on so that they may be acted upon—would you not think the presence of the advocate would speed healing?

**Ms Campion:** The thing is, we often think of communication as simply an exchange of information. If that is the case, then the advocate is fine, but I think communication is about relationship. That is when I start to worry about the advocate, because the advocate comes in as an outsider, apparently to be objective, I suppose, and does not necessarily build relationship with the patient or resident, the health care team or with the family. So we are dealing with a very narrow view of communicating. I think healing is dependent on the larger view which involves the relationship aspect of it.

**Ms Carter:** But I think the point here is that we are not dealing with that majority of people who have no problems as far as their family and medical attendance go. We are dealing with those people who fall between the cracks.

**Mr Sterling:** We are dealing with everybody.

Interjections.

**The Chair:** Order, please.

**Ms Carter:** I am talking about the Advocacy Act as such.

**Mr Sterling:** We are talking about the Advocacy Act. It affects everybody, every treatment that they can get—that is the problem with it.

**Mrs Sullivan:** They have more powers than the police do.

**Ms Carter:** No, the only power they have is to go into a place where they think there may be a vulnerable person who would wish to speak with an advocate and to be allowed—

**Mrs Sullivan:** Access to records?

**Ms Carter:** —to speak privately with that person. They would leave immediately if that person did not wish them to be there. They have none of the powers the police have to bring consequences.

**Mr Sterling:** They have more powers.

**Mrs Sullivan:** They have more powers than the police. They have full access to clinical records.

**The Chair:** Ms Campion, a quick response.

**Ms Campion:** I do not know how we look at hospitals. I tend to look at them as moral communities. My fear is that when we work with the idea of advocates, we will be diverting tremendously needed resources from the building of moral communities in hospitals to shoring up the adversarial nature of the relationship. So we are making a choice and we are going, to my mind—I am an ethicist; I get to say it—with a wrong stream.

**The Chair:** Sister Marcella, Dr Crowell, Ms Campion and Ms Cary, on behalf of this committee, I would like to thank you for taking the time out to come and give us your presentation this afternoon.

#### CANADIAN ABORTION RIGHTS ACTION LEAGUE

**The Chair:** I call forward our next presenters, from the Canadian Abortion Rights Action League. Good afternoon. I just remind you that you will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, can you please identify yourselves for the record and then proceed.

**Ms Toogood:** My name is Joan Toogood. I am a board member of the Canadian Abortion Rights Action League. With me is Jane Holmes, CARAL's executive coordinator. We are pleased to be able to appear before this committee.

The Canadian Abortion Rights Action League is an incorporated, non-profit organization which has been working for the past 18 years to ensure that criminal laws on abortion are abolished and that no woman in Canada is denied access to a medically insured abortion. We have about 18,000 individual members in Canada and roughly 60% of those reside in Ontario.

The government's package of health legislation is generally humane and is certainly comprehensive. CARAL would like to thank the government for its good intentions in introducing this package of legislation which is designed to benefit a great many people. The one group which some portions of this legislative package hurts, however, is pregnant women, especially young women.

The age of capacity to consent to treatment, age 16, which is found in sections 8 and 10 of Bill 109, would likely prevent access to health services, particularly abortion services.

Bill 8 creates an exception for pregnant women who have made living wills.

We will now review the portions of the legislation with which we have concerns.

Consent to Treatment, Bill 109: Section 8 includes a presumption of capacity above age 16 and a presumption of incapacity below that age.

We understand this section is an attempt to codify the common law. We respectfully submit, however, that at common law there is no presumption of incompetence below the age of 16. What is needed for a child to be considered mature enough to be capable of giving informed consent is the requisite mental ability to understand the nature and consequence of the proposed treatment. We agree with the proposed amendment put forward by the Progressive Conservative Party that eliminates age references in section 8.

If a presumption of incapacity based on age is created by legislation, we believe the government will be legislating a serious erosion of children's rights at common law. If, however, the government insists on creating such a presumption, then this presumption must be set at a significantly lower age, which more reasonably reflects the concerns and responsibilities of young people in today's world.

In fact, data indicate that many young people are sexually active by age 12. There is significant sexual activity among 12- to 14-year-olds, which is known by the incidence of accidental pregnancies and sexually transmitted diseases in this age group. Recent research shows that one quarter of Alberta's adolescents have had sexual intercourse by age 14. The figure for the United States for teens in grade 9 is 40%. In 1989 there were five live births recorded for children age 12. For the age group 12 to 14, there were 214 live births and 354 abortions.

We recognize that the presumption currently set at age 16 is rebuttable, but we agree with the consensus among professionals in the field of reproductive health that many doctors will not actually rebut the presumption.

We have all witnessed the great fear of liability the medical profession displayed during the debate on the federal government's Criminal Code abortion legislation.

#### 1450

If the proposed amendment to section 8 is adopted, section 9 and clause 45(d) become unnecessary. It is of concern to us that the regulations have not been drafted and may make it difficult for pregnant women to be deemed capable in a timely way. As professionals, doctors are the ones who should make determinations of capacity, without direction from legislators. It is part of being a professional to have the ability to establish such standards.

We move now to section 10, which deals with advocates for persons who have been found incapable. Subsection (7) states that the provisions of section 10 apply to persons under the age of 16 who have demonstrated a wish to give or refuse consent on their own behalf. This section appears to apply to anyone under the age of 16, whether or not there has been any finding of incapacity and whether or not there has been any opportunity to rebut such a finding.

This is a problem because it appears to force all persons under the age of 16 to submit to a review process. We would like the age references in this section removed so that section 10 refers only to those specifically and individually found by physicians to be incapable of consenting on their own behalf, whether they are 16 or not.

The Advocacy Act, Bill 74: In this act, provision has been made for commissioners to represent the interests of various constituencies of vulnerable persons. Among other things, the commissioners shall ensure that such persons can obtain necessary advocacy services and shall appoint advocates. Commissioners and advocates are to have appropriate expertise in the area of vulnerability as well as in the area of recommended action.

We would like to be assured that selected commissioners and advocates will adequately represent the rights of women. Therefore, we believe that half of these appointed commissioners and advocates should be women who have demonstrated a concern for women's equality. This is a somewhat general statement, and perhaps it would have to be redefined if it were drafted in legislation. We leave that to you. But vulnerable persons who are women may be pregnant, and the structure of the system of advocates should not result in anti-choice people being appointed to act for such persons. Just as vulnerable persons with Alzheimer's disease or with physical disabilities need an advocate who understands their condition, so pregnant women need advocates who know how fundamental the right to choose is to women's equality. Advocates should not have personal or religious agendas that prevent them from advocating on the whole range of legal options available to the incapable or vulnerable person.

The concerns expressed here regarding advocates and commissioners appointed under the Advocacy Act also apply with respect to the composition of the review board described in section 10 of the Consent to Treatment Act. The Advocacy Act will presumably apply to the advocacy system described in section 10 of Bill 109. We note, however, that the Advocacy Act currently does not apply to those under the age of 16. Once again, we would like to see this age limit removed, as we believe that youth may be among those vulnerable persons most in need of protection.

An Act respecting Natural Death, Bill 8, and the Substitute Decisions Act, Bill 108: As an organization concerned primarily with a woman's right to choose in the matter of abortion, we strongly believe a woman's individual rights should not at any time or in any way be curtailed because she is pregnant. Pregnant women must be accorded the same rights as everyone else, and therefore the living will of a woman who is pregnant should not be invalidated because of that fact. Dying women must not be turned into unwilling incubators by the state.

In Bill 108 the government did well to draft a bill which does not make an exception of pregnant women. We hope the committee will confirm this version of the legislation and defeat any amendments which would make such an exception of pregnant women.

Bill 8, submitted by Mr Sterling, contains a clause which makes a woman's living will invalid when she be-

comes pregnant. CARAL urges the committee not to vote in favour of this legislation.

Consent and Capacity Statute Law Amendment Act, Bill 110: We believe that the regulation under the Ontario Public Hospitals Act requiring a person to be 16 years of age to sign a consent to surgery should have the age references specifically removed or should be struck out entirely as inconsistent with the Consent to Treatment Act as we would like to see it amended. The age requirement for a signed consent to surgery has always caused us a great deal of concern and has had a significant effect on doctors' perception of their duty to young teens requesting abortion. It has also likely caused some of the confusion concerning the position of the common law with respect to the age of consent. This legislation may in fact be partly responsible for many doctors' and lawmakers' belief that the common-law position concerning consent rested at age 16. This regulation of long standing does not take account of the fact that today half of young people aged 16 are sexually active and may require abortion services.

We hope that the consent to treatment legislation, because any definition of "treatment" would certainly include surgery, will supersede the age restriction for signed consent regulation in the Public Hospitals Act. Therefore the removal of an age limit in the Consent to Treatment Act would effectively remove any age barriers to consent with respect to surgery performed in a public hospital. If this is not the case, we ask that age references be removed from the Public Hospitals Act and doctors simply evaluate capacity based on their own professional judgement, and obtain informed consent.

Our recommendations:

1. To replace the current section 8 with the amendment proposed by the Progressive Conservatives. Such an amendment will eliminate the need for section 9 and clause 45(d) contained in the current Bill 109. Standards and criteria for determining capacity shall be the responsibility of individual health practitioners and not legislators.

We also support the Progressive Conservative amendments regarding the definition of "treatment."

2. We recommend that subsection 10(7) be removed from the proposed legislation and that subsection 10(1) be amended to apply to all persons found incapable, regardless of age.

3. Half of the commissioners and advocates should be women. Advocates appointed to represent vulnerable women should have demonstrated a belief in women's equality. We believe the same criteria should apply to the review board constituted in section 10 of Bill 109.

4. We recommend that the committee vote against any legislation which contains a provision which would make a living will invalid if a woman becomes pregnant.

5. We recommend that the age reference be removed from the Public Hospitals Act with regard to consent to surgery.

Thank you for your attention. We welcome any questions you may have.

**The Chair:** Thank you. Each caucus has about five minutes.

**Mrs Sullivan:** I think that one of the areas where we have apparently reached consensus on this committee relates to the recognition of the mature minor. Indeed, when the Minister of Health was before the committee she indicated that there would be amendments in that area. We, of course, have been pressing to see the amendments, and in fact to see whether they meet the needs of the groups and agencies that will be required to act under the law and that the law may or may not benefit, but the government has been reluctant to put those forward.

You have mentioned the regulations under the Public Health Act being affected, and I am sure the parliamentary assistant will want to take that into account in terms of the age issues. We have also noted that there are serious age issues associated with consent to treatment under the Child and Family Services Act where a child may be a ward or in a foster home or where there may be intervention in the case of the gathering of evidence for incest investigation purposes and so on.

1500

I was also struck in your presentation, juxtaposed as it was with the previous presentation, and the emphasis of both groups—one would assume whose moral judgements are quite different—stressing the necessity for the independence, for the neutrality, if you like, of moral and religious judgements on the part of the advocate and, in fact, for the advocate to have knowledge of the patient's moral, ethical and religious judgements before participating in any way to put forward the patient's case or even to provide advice. I thought that it was quite interesting and pertinent for the work of the committee that those issues have been put on the table not merely from one ethical perspective but virtually from several, and I know that that has been a concern.

You see the young advocate as having an impact on the decisions of the patient. Clearly we do, as evidenced from the exchange during the last session. The government does not appear to see that the advocate would have any influence, even given the quite extraordinary powers that the advocate has under this legislation. I wonder if you have examined where an advocate indeed may have a negative impact on the autonomous choices of a patient.

**Ms Holmes:** First of all, we are concerned that advocates not be called in unnecessarily and that patients, because of dealing with fearful doctors or doctors who want to do things properly but now that there is an extra burden of legislation in effect will be bending over backwards to invoke whatever powers they need to invoke, will have advocates who do not need advocates—15-year-old girls who are pregnant, for instance. We are also concerned that if they are going to have an advocate because perhaps they are genuinely incapable of making their own decision, then those advocates ought to be people who will tell them about all of their legal options.

It is not so much a matter of my perspective or your perspective or if I am taking on the perspective of the patient. But in the case of abortion, someone might presume that if you come from a certain religious background you are going to be someone who does not believe that you should have an abortion. This may not be the case. We

know that Catholics, for instance, have abortions in about the same proportion as the general population and they are pro-choice in about the same proportion. So it is an attempt to avoid this type of coercive situation that we express our concern that the commissioners and the advocates be selected from not just certain volunteer groups or people who—there should be some care exercised in who is picked. They should have to agree that they are going to present all of the options to any patient whom they are helping.

**Mrs Sullivan:** Thank you.

**Mr J. Wilson:** Thank you very much for your presentation. I particularly appreciate the support of two of our amendments. I note you do not support one of the sections in one of Mr Sterling's acts, but I would remind you that it is a private member's bill; do not hold it against all of caucus.

Interjections.

**Mr J. Wilson:** Two out of three ain't bad, as they say. But really, in all seriousness—

**Mr Winninger:** We thought you were being serious.

**Mr J. Wilson:** I was. We believe in free votes. You thought the Reform Party made that up, but look at the record of our party over the years.

None the less, I was really going to ask you the same line of questioning as my Liberal colleague. That is one of the disadvantages we have. For some reason the Liberals on this committee always get to go first rather than alternating who asks questions first.

**Mrs Sullivan:** Next election, you will be in opposition.

**Mr J. Wilson:** Well, that is true.

**Mr Sterling:** We will be leading.

**Mr J. Wilson:** And I do not think the Liberals will be leading.

None the less, because it did strike me that you are worried about some bias on behalf of advocates also, and the government consistently tells me—although we get mixed messages on exactly what advocates are supposed to be doing, the more consistent answer we get is that they simply express the views as articulated in some manner by the vulnerable person. Is that what you see advocates doing? There are advocates out in the community now that do that and other things.

**Ms Holmes:** Yes, that is right. I think it is entirely possible for them to do that but I think we just have to watch how they are selected and who they are.

**Mr J. Wilson:** You mention selection, but what about accountability in the system? This is an arm's-length commission now and there is really no accountability. Where do you complain if you find an advocate that has a religious bias that may be distorting the decision of the vulnerable adult? Where would you go?

**Ms Holmes:** I suppose you would go to the commission. You might have to call on the government. You might have to go right to the top.

**Mr J. Wilson:** I think it points out the problem because this is at arm's length from the government.

**Ms Holmes:** But we have these problems—

**Mr J. Wilson:** A biased commission.

**Ms Holmes:** We, as an interest group, have these problems throughout all of the institutions in society. We cannot do away with the department of education in all the schools just because there are some teachers who are anti-choice and are preaching their views from their positions in the classroom. Yet we have that. There are school boards that make abortion a taboo subject. We have to complain about these things. Eventually, we will make some changes.

**Ms Akande:** Thank you very much for the presentation also. I was interested in your description. Certainly the need for advocacy has been long established, even previous to our coming to power. Certainly the O'Sullivan study estimated that we would need approximately a million advocates in Ontario and there have been other studies even before that time.

When one sets out to design an advocacy system and they draw their net widely, not only in terms of the design of the program so that it is in place for those who may need them, but also in terms of the selection of those who will assume the role so that they may do their job with the kind of objectivity you think is so important. Your words are well taken. One of the things I was concerned about, though, is that in your recommendation 1, for example, you say "Standards and criteria for determining capacity shall be the responsibility of individual health practitioners and not legislators."

**Ms Holmes:** We believe that doctors ought to be the ones who have the responsibility for determining whether a person is capable or not. Otherwise, it is something that has to be—you have to call in a complicated system for everyone under age 16, unless the doctor has decided to rebut that presumption, but we do not believe doctors will do that. We think they will just take that age 16 as a cutoff and when they get a person under that age they will not do anything about it. They will just say, "Well, you're under 16 and I am worried that your family may be upset about this and I can't ensure your confidentiality etc."

**Ms Akande:** I can see your concern about 16 and I share it. Let's be frank and say that to you. But I also have concern about it being left up to the individual health practitioners to call it, with a great deal of variation, perhaps, in terms of what one might see as a capable person or a young person and what another may not. Would you expect that there would be any intervention at all, perhaps criteria by which people might assume or try to draw some kind of standards for making that decision?

**Ms Holmes:** The problem is that whenever you get into trying to write it down and draw up standards, these can be a stumbling block which delays treatment. In the case of pregnant women in general and teens in particular, there is no time for all of this paperwork. We are worried about referrals to other practitioners and other specialists. You know: "Let's see if you're capable. I will give you a psychological test or I'll send you to an agency that will do a battery of tests to determine if you're capable."

**Ms Akande:** No, I am not suggesting that.

**Ms Holmes:** I would say clause 45(d) would be very intimidating if I were a doctor.

**Ms Akande:** Would you concede that perhaps there might be a role for an additional person, in combination with a doctor, to assist in this determination?

**Ms Holmes:** Why complicate the process?

**Ms Akande:** Because those who have sometimes been responsible for it may in fact be the very people against whom you want to question.

**Ms Holmes:** I think the government is then getting in between the doctor and the patient, and that is something we take a very dim view of. We want to have our privacy with the doctor, and if we want an abortion, we want to be able to deal with that as a private matter between the patient and the doctor.

**The Chair:** Ms Toogood and Ms Holmes, on behalf of this committee I would like to thank you for taking the time out this afternoon and coming and giving us your presentation. While we set up the VCR, we will have a brief recess.

The committee recessed at 1512.

1526

**The Chair:** I call this committee back to order.

QUEEN'S UNIVERSITY, FACULTY OF LAW

**The Chair:** Our next presenters are from Queen's University, faculty of law. Good afternoon. As you know, you have a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Ms Reitsma:** Good afternoon. My name is Kelly Reitsma.

**Ms Putnam:** I am Violet Putnam. I am not a professor. I am a student at law.

**Ms Hodgson:** My name is Lenore Hodgson.

**Ms Reitsma:** Today what we will first be doing is watching a video presentation. In it, myself and Ms Hodgson interview Miss Putnam. It was meant for a class presentation, so it is a little bit amateurish. We hope it does not insult you in any way.

**Mr Poirier:** It is okay. We are MPPs; do not worry about it.

**Ms Reitsma:** In it we feel there is something really useful. We interview a senior member of the Kingston community. We hope you find that very useful in this respect. I will just turn it on now.

[Video presentation]

**Ms Putnam:** We are going to fast-forward through this part because we do not think it is very relevant and we will start in with the interview with the 74-year-old lady in Kingston. She is a very articulate senior citizen and has some really progressive ideas that I think would be good for all of us to hear.

This lady runs a program of swimming for people who need aquacise in the pool in a rehabilitation hospital in Kingston, St Mary's of the Lake, and organizes the whole thing. I think there are three classes three nights a week and she has them topped up with a waiting list. She is there almost every time and she has a deputy to fill in for her and she is 74 years old.

I was speaking to someone here a bit ago—it is not an original idea; I read it—and said these seniors who are presently coming on board the senior citizens' platform and those who will be joining us annually are probably the best-educated senior citizens Canada has ever known, so there is going to be a pool of knowledge and experience there that we should perhaps access.

[Video presentation]

1540

**Ms Reitsma:** I thought I would cut it off a bit early because we are getting close to the time. In our brief it may seem a little bit conflicting: We encourage the implementation of advocacy services and at the same time we encourage increasing lines of communication for family members, and this we see in Bill 108, section 17. Placing public trustee representatives in each region is outlined on pages 1 and 2 of our brief. I feel that both vulnerable persons and their families both must be accorded respect and participation in the mental health law regime. In that regard, I believe our proposal fosters the necessary cooperative spirit.

The proposals outlined on pages 1 and 2 in relation to families of vulnerable persons are intended to reduce frustrations that families presently experience with the office of the public trustee and accord the family respect in a way that reduces its ongoing stress.

The qualified advocate may also play a role, we feel. This role of the advocate may be expanded in Bill 74 and Bill 108 to allow the advocate access to financial statements. This may be viewed as an intrusion by family members, but we cannot always assume the family members are going to act in the best interests of the vulnerable person.

As I see it, there is lacking in Bill 74 a mechanism for fostering communication between the family and the advocate. This is addressed perhaps in clause 7(1)(h) in Bill 74, but it is really limited and it is not just for the family. I see this as a way of fostering a cooperative atmosphere and also reducing the workload of the advocates, as the family perhaps can take on more responsibility and understand the process better. Perhaps the adversarial orientation in Bill 74 needs to be refined in this way. I believe it is in everyone's interests to encourage this cooperative relationship.

**Ms Putnam:** My concern today stems from the Cedar Glen episode—my presentation is on page 3—and the death of Mr Kendall, because there was no way anyone could get into that place for a year to rescue him and his fellow patients, or guests or whatever they were called, from an abusive situation. As I recall, one woman was so badly injured she went to hospital for eight months, but nothing happened. It required Mr Kendall to die before

somebody could get in there. They went to the advocate office in Toronto; they could not get in. They went to the police; they could not get in. Officially, nobody could get in because it was private, even though they were living on public funds they got for looking after the patients. My concern is that if the bill cannot be passed right away, could we have some interim emergency legislation put in place to address that problem?

I have looked at Bill 74, and from section 16 to section 23 is the advocate's right to entry. I would like to see that section modified and either set up as an emergency situation or woven into existing laws. I looked over the Powers of Attorney Act. It could be inserted in section 8. I looked over the Child and Family Services Act and saw that it would fit nicely in section 40 or section 40d; also section 71, which is a child abuse register. If the abusers at Cedar Glen get out, I think they should be on a register. I do not think they should be allowed to go out and set up a new setup. I mean, the money is pretty nice, especially when you do not have an education, you do not have a trade, you are middle-aged, and if nobody knows you. I just think the doors should be closed and their names should be on a register.

I would like to see, as in the case of child abuse, that if people do not report offences they are fined. That is part of the Nursing Homes Act, that if people do not report abuse they observe or know of, they are subject to a fine and/or jail term. Children are precious, but elderly people's pain receptors are just about as acute as those of children. It is terrible to have to wait a year to be rescued. It is terrible to wait a week to be rescued from an abusive situation.

On page 4, I have an excerpt from the actual court case regarding Mr Thibeault. I prepared this for a class. Those are the horrible things that happened to him before he died. I believe that was reported by the staff, but there was nothing in place to say that the staff would be punished if they did not report it. In fact, if they did report it I assume they would lose their job.

This is another thought I had. Using the Mental Health Act, the official guardian is listed under section 1a as a substitute decision maker. Could we expand his role and the agents he has in place in every area in Ontario? If there is a report of abuse, perhaps the official guardian could send a note and say, "Please investigate." I know they are all lawyers, but they are better than nothing, and nothing is what we have right now.

**Mr Winner:** I wish to dispute that.

**Mr J. Wilson:** Did you get an A on that project?

**Ms Putnam:** I got an award.

I feel very strongly about it and I am quite upset that we could sit and talk about what is good about Bills 74, 108, 109 etc, and there are people right now—I have to be careful not to say the wrong thing, but I have talked to people who are dealing with people who are abused and they know that abuse is going on but they are powerless to do anything about it because in their organization they do not have the power.

They go to work and they spread the word among people who would refer people to live in that place and

pay \$1,500 a month—it is not unusual—and if you have five people at \$1,500 a month you have a pretty good income. Elderly people do not eat much. They just like to be warm. They quietly spread the word this is a bad place and patients stop going there. One person I talked to said they had shut down three, quietly, but their organization is at risk and they personally are at risk and yet they feel so upset about these people being abused that they put themselves on the line. I do not really think it is fair that they should have to put their careers or their organization on the line when it is something that should be legislated and that they have the power to do.

1550

If there is no money to put it in place right away, I suggest that we use existing organizations like the Victorian Order of Nurses. They go into homes and they are accepted; public health goes into homes regularly and they are accepted and trusted. They have a good track record of being trustworthy and caring people. The Community and Social Services people are the same way. That would give protection to the people who are sitting there and are so vulnerable and yet would give time to build the structure required by these bills. That is what I feel strongly about.

We are talking about advocates. The three of us all did placement work at Kingston Psychiatric Hospital and we saw the patient advocates at work. They do some good work, but there is also a need for training. Perhaps you could tell us what you observed on the review board.

**Ms Hodgson:** I have canvassed a number of psychiatrists and some have been impartial to the advocates, some have been resentful and some have found them very helpful. I have really one proposal to make to this committee: that it integrate some sort of workshop into the system for training of the advocate. From what I have seen attending review board hearings and just normal interaction in the hospitals, there is really no integration between the psychiatrists and these advocates. They are sort of portrayed as the devil and they are not integrated into the system. What I propose is some sort of workshop or some sort of training before they are actually implemented to a fuller scale. Thank you.

**Mrs Sullivan:** I am interested in the questions you raise about the training of advocates and so on. We are very concerned under this legislation. It may make a nice next project for you to look at the entire question of the scope of mandate of the advocates being developed through regulation without public input and without definition of indeed the kinds of training and the kinds of skills that would be required.

In a health setting, for example, I suggest to you that it is useful for an advocate to have information about the nature of the treatment and the nature of the illness before that advice is being presented. In Bill 74 we see that advocates have powers of entry that are greater than the police now have. In Bill 74 we see that advocates have the right of access to clinical records that we feel is problematical. I think that maybe in the next phase of your project you might like to look at some of those issues.

There have been suggestions that we think are very interesting ones about using a pilot project. As you define one community and look at existing agencies where advocacy does exist and is put in place in a substantial way, the circumstances in one community may be very different than the circumstances in another.

One of the things you did not raise that I think is very important is that we have had very clear testimony before the committee that the advocate's role may indeed interfere with the provision of timely and appropriate health care. That is one of the things where, while it was not the intention of the act, it is clearly the result of the legislation if it is written this way. We are told that amendments are coming forward. We have not seen those amendments. We are very concerned that we have had numbers of weeks of hearings with people presenting on the bills as they are written, with no access to or information about proposals for amendment to those bills, and indeed no commitment of the government that there will be a public consultation process after those amendments are put forward. There is another term paper for you.

**Mr J. Wilson:** I thought it was a very balanced presentation, actually. You point out support for the bills but also some improvements. You also touch upon the financial aspects, and I do appreciate your comments that perhaps the VONs and the health care units and that do now act as advocates, and that is something we have heard before the committee and it is something we have tried to point out to the government: that you may not have to go to the expense of setting up a new Advocacy Commission.

I do want to ask you a question, though, because you have had experience in the mental health setting where an advocate is present and you have witnessed something of an adversarial relationship. Do you see anything in Bill 74 that would diminish that adversarial relationship?

**Ms Putnam:** Whom are you asking?

**Mr J. Wilson:** Whomever is comfortable with that.

**Ms Putnam:** I think they are trying to leave it open to the community, to the family, to already established organizations in the community, and I think that could lead to the choice of an advocate who would be more open and not so adversarial. I did volunteer work at the Homewood Sanitarium, and it and the Royal Ottawa Hospital have the volunteers doing the advocacy. I found a much better relationship there between the staff and the advocates than I see in—I have only been to Kingston Psychiatric Hospital, but there is an adversarial relationship in the public hospital. There is a very cooperative relationship where the volunteers are going to the floors—They seemed to welcome me with open arms when I went up; the files were out, they took me to the rooms—but in KPH there was not a connection between the advocates and the staff, so I would like to see that changed.

**Mr J. Wilson:** Very briefly, though, I was disturbed to hear of people who may be aware of abuse and are afraid to report it. May I suggest if the current system is so backlogged that people cannot access reporting mechanisms there—for instance, I know it will be two years before the Ombudsman's office gets around to it. If someone does not

want to go to the police, perhaps in confidence you can go to your local member of provincial Parliament—

**Ms Putnam:** That is right.

**Mr J. Wilson:** —who should be doing that in that community. So you might suggest that. Some people do not think of that avenue. They think of all these other structures, but MPPs there can do exactly that.

**Mr Malkowski:** The three of you gave a very excellent presentation. It was a great project. It is very educational for all of us here on the committee to hear the views you express, and we appreciate your support for our legislation to protect vulnerable individuals. I would like to know, from your own experience in meeting with the professional health care workers, did it seem that there was a lot of resistance to the concept of advocates going in to talk with vulnerable individuals, and how would we then alleviate that kind of resentment if that was the stance of some of those professionals? What would you suggest?

**Ms Putnam:** We cannot seem to think of anything we have not already said.

**Ms Reitsma:** Lenore had a very adversarial experience and a very confrontational experience when she was there. There are a number of things that happened. Lenore suggested workshops.

I see Bill 74 as very adversarial. I see that one way of reducing all those tensions is fostering a cooperative spirit between families and the advocate and, in some way, fostering a relationship between the advocate and the psychiatrist, which is very difficult. There is a lot of confrontation between people who want to assert rights and the psychiatrist who wants to help. That always happens between the law and psychiatry, and in this regard it is also—I do not know if there is any one way to solve it. I think it is very difficult.

**Ms Putnam:** There is a British author who stated that people have the right to refuse treatment, and the advocates seem to go on the side of, "You can refuse treatment; it's your right." But this British author stated—and I agree with him—that there is a point where, if treatment will get these people off the rolls of disability so that they can be self-sufficient, do they have the right to be for ever ill when it is possible for them to be made well? Where do we draw the line? Where do the rights of those who have to pay the bills have some impact on the cost of allowing these people to stay sick? There should be a cutoff point.

**The Chair:** Ms Reitsma, Ms Putnam and Ms Hodgson, on behalf of the committee I would like to thank you for taking the time this afternoon and giving us your presentation.

1600

#### ROYAL COLLEGE OF DENTAL SURGEONS OF ONTARIO

**The Chair:** I would like to call forward our next presenters from the Royal College of Dental Surgeons of Ontario. Good afternoon. Just a reminder that you will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and com-

ments from each of the caucuses. As soon as you are comfortable could you please identify yourself for the record and then proceed.

**Dr Beyers:** Yes, thank you, Mr Chair, and members of the committee. My name is Dr Richard Beyers. I am the president of the Royal College of Dental Surgeons of Ontario. With me are Dr Minna Stein, the deputy registrar of the college, and Mr Alan Bromstein, legal counsel for the college. Just to remind you, it is the college's role to govern the practice of dentistry and, for a short while yet, dental hygiene in Ontario, and to do so in the interests of the public. Without going any further myself, I think I will turn this over to Dr Stein who will make the presentation.

**Dr Stein:** Let me begin by stating that the college fully supports the principle that a person has the right to determine whatever treatment he or she will receive. It also unconditionally supports efforts to ensure that a vulnerable person is not subjected to health care decisions without first obtaining that person's input and in appropriate cases an independent assessment of the capability of that person to consent to the proposed treatment. Unfortunately, unless substantially amended, the proposed legislation, and in particular Bill 109, may have negative effects on the health care provided in Ontario.

Let me elaborate on the college's major concerns. We believe that the scope of the legislation is too broad; the legislation applies to all treatment. This term is defined as including not only therapeutic intervention, but also preventive and diagnostic measures. Therefore, in practical terms, a patient undergoing a clinical examination is given the same legal protections as one having major surgery. While this is philosophically laudable it is not practical or, in the college's view, necessary.

Furthermore, the legislation applies equally to health practitioners regardless of what they do. As a result, the same safeguards are in place for health practitioners who do not perform any invasive procedures, such as denture therapists or dental technologists, as for those who do, for example dentists, dental hygienists and physicians. The college is of the view that the scope of the legislation must be narrowed so that only certain forms of treatment would be included.

Some treatments, such as those that are serious or irreversible, require the intervention of this legislation to ensure that the interests of the vulnerable patients are protected, while other forms of treatment, such as simple dental examinations, ought not to attract the same complex bureaucratic procedures. As you are aware, this is a view that is also supported by the Regulated Health Professions Act, recently given royal assent in the Legislature. In that legislation, only certain acts which are considered potentially harmful are controlled or restricted to regulated health practitioners. All other health-related acts are in the public domain and hence can be done by anyone.

Unfortunately, the provisions of Bill 109 are adverse to the controlled act concept in that (1) all treatment is given the same degree of protection whether the treatment is inherently dangerous or not, and (2) all registered health

practitioners are required to follow the bill's procedures regardless of the nature of the treatment to be performed.

Furthermore, as currently proposed, when a regulated health practitioner performs treatment which is not a "controlled act," the provisions of Bill 109 would apply. However, should the same treatment be provided by an unregulated person, the provisions would not apply. This clearly could not have been the intention of the legislation.

What is needed is a clear understanding of exactly what types of treatment require protection for the vulnerable patient. If protection is required, the legislation should be made applicable to anyone who may legally perform the treatment.

Another area of concern to the college is who should be included in the term "incapable" under Bill 109. We feel the legislation does not adequately address the practicality of including all children, regardless of age, under that term.

An example to illustrate this point is a situation where an extremely sophisticated but fearful 12-year-old child attends the dental office with a badly decayed tooth and adamantly refuses to allow the dentist to give an injection of local anaesthesia to treat the tooth, although it is clear the child is in pain. The parent demands that the dentist treat the patient. The child not only expresses the view that the dentist should not treat him, but that he has the right to make his own decision and that the dentist should not listen to the parent. Believe me, having been a practising dentist for many years, that does happen.

The practitioner knows that if the local anaesthesia is given, the child will be pain-free and will calm down and ultimately be thankful for the treatment. He also knows that without the treatment, the pain will increase, the infection may continue and further complications will likely result, including the loss of the tooth.

Is this the type of case where an advocate should be called? Is it responsible to ask a dentist to tell the parent that the child cannot be treated until the procedures of Bill 109 have been followed? Do you believe the public of Ontario would accept such a response from a dentist?

The college does not believe it would be responsible to delay treatment in order to determine whether the 12-year-old child is capable, especially considering the nature of the proposed treatment and the procedures required by Bill 109.

Furthermore, the sections of the bill dealing with emergency treatment need substantial change. A practical example of problems related to this is a case where an eight-year-old child is brought in to the dentist's office by a neighbour. The child presents with his front tooth in his hand. There is no medical risk in doing nothing, but there is a reasonable chance that the tooth may be successfully reimplanted if immediate treatment is given. Neither the parents nor any other consent giver can be found. Any delay on the part of the dentist, however, will make the success of the treatment less likely.

Reading section 22 of Bill 109, it is unlikely that any dentist could attempt to save the tooth, because the patient is not likely to suffer any serious bodily harm if that dentist were to do nothing. The child simply would have permanently lost the tooth. We believe that today a dentist would

treat the child and attempt to reimplant the tooth. That dentist would then ensure that the parent or the guardian of the child was contacted and that the risks associated with the treatment were explained. If the parent or the guardian did not wish to accept those risks, the treatment could easily be reversed and no harm would have resulted. Most likely, however, the parent or the guardian would be grateful for the dentist's efforts in attempting to save the tooth. That has certainly been our experience.

#### 1610

The college is seriously concerned that this legislation may create such apprehension in the minds of practitioners about their personal liabilities that the safe route would be taken; that is, that no treatment would be provided. If this happens, the patient obviously would be the loser.

We believe that children and the problems associated with obtaining adequate consent for their treatment deserve their own unique considerations. We are concerned that the affording of Bill 109 protection to all children under 16 years of age will either cause the legislation to be ignored or will have a profound negative effect on health care administered to children of this province.

The college's second major concern is that the legislation is too complex. In examining Bill 109 one must always remember that it is the practitioner who has the gatekeeper's duty to ensure that consent is obtained. The college has spoken to many dentists who, despite reading and re-reading the legislation, do not understand what they are required to do. As well, these practitioners ask meaningful questions arising out of practical examples which occur frequently in their offices. The answers to these questions are difficult for both laymen and lawyers to provide, and in many cases the answers cannot be given with any certainty.

For this legislation to be effective, it must be simple and easily understood. It should provide to the practitioner who attempts in good faith to follow its instructions a confidence that no liability will follow from that practitioner's actions. The legislation must also be looked at in the light of practical examples to see if it will work in the manner intended without negative implications. The worst of all situations would arise if practitioners ceased to treat vulnerable patients due to the complexities and uncertainties of this legislation.

The third major concern related to Bill 109 is that it inappropriately alters the law of informed consent. The doctrine of informed consent is one which provides needed protection to the public. This doctrine is accurately and fully described in legal jurisprudence including the Supreme Court of Canada's decision in *Riebl v Hughes*. As the Supreme Court of Canada has indicated, it is a doctrine associated with the law of negligence and not with the law of assault and battery.

The doctrine of informed consent requires a practitioner to advise the patient of material risks. However, liability for failure to advise of a risk of treatment does not follow unless harm from that treatment has occurred and a reasonable person, having regard for that patient's personal circumstances, would have refused the treatment had that person been made aware of the risk. This doctrine balances

the need to protect the public with the rights of the practitioner. It also is clearly understood currently by health professionals.

Bill 109 attempts to put the doctrine of informed consent into precise legislative words. By doing so, the draftspersons have unwittingly, and without legal or logical basis or need, expanded the concept.

An example of this may be the situation in which a practitioner consults with a patient who is clearly capable. The patient is seeking treatment for a badly decayed tooth and the dentist recommends a crown. Some of the risks associated with the treatment are discussed. However, the dentist neglects to describe the alternative course of treatment—namely, the extraction of the tooth—and, further, neglects to tell the patient of a risk, namely, that the tooth may require endodontic treatment in the future. By virtue of subsection 5(2) of Bill 109, an informed consent has not been given. Does this mean that the dentist, by law, assaulted the patient when he performed the treatment? Does it mean that the dentist is liable for the failure to describe the risk even if the risk has not occurred and may never occur?

As proposed, Bill 109 allows virtually all patients to claim that one or more aspects of informed consent have not been met. Furthermore, the legislation does not adequately explain what the practitioner's responsibility is for failing to obtain informed consent. The doctrine of informed consent does not need to be modified by this legislation. To do so would give rise to additional litigation where lawyers will use the provisions of Bill 109 to argue that the law, as previously expressed by the Canadian courts, has been altered.

In summary, I would like to summarize that we would recommend the following amendments to Bill 109:

The first recommendation is that treatment be redefined to include only those health care services that are potentially harmful, and for some other reasons significant to the patients who are intended to be protected by this legislation. To be both meaningful and effective, protection should be afforded to the vulnerable person where that protection is reasonably necessary. The nature of the protection to be afforded must be flexible and based upon the nature of the treatment and the particular circumstances of the patient.

The second recommendation we have is that except for those surgical procedures which require treatment in hospital, dental care be excluded from Bill 109 relative to all children under the age of 16 years. Whether protection is to be afforded to a child under 16 years of age should depend upon the nature of the treatment. In the college's opinion, only those aspects of dental treatment which may be performed in hospital are sufficiently serious to warrant a change in the current practice of obtaining consent from the child's parent or guardian.

The third recommendation we have is that the doctrine of informed consent be eliminated from Bill 109. As previously indicated, the doctrine of informed consent is one which has been developed in the law of negligence. The issue as to whether a practitioner failed to obtain informed consent is one to be dealt with by the courts based on

current jurisprudence. There is no need for legislation to change the law and Bill 109 should not attempt to do so.

The fourth and final recommendation we have is that the legislation be made simpler and provide greater certainty for those practitioners who, exercising good faith, attempt to comply with its provisions. The true test of legislation is whether practitioners to whom it is applicable can understand what is required of them. If those practitioners perform treatment in a manner they reasonably believe is consistent with the legislative intent, no criminal or civil liability based solely upon treatment without valid consent should follow.

In conclusion, I would like to say that we are hopeful our recommendations will assist you in making the amendments you feel are required to enhance the proposed legislation.

If you have any questions, I would be more than happy to answer them. Thank you very much for your attention.

**Mrs Sullivan:** Thank you very much for this presentation. I particularly appreciate the discussion you have included at the beginning of the presentation relating to the controlled and authorized acts. It seems to me it is quite clear that there is going to have to be a major redraft of the "treatment" definition in this legislation, and that distinction may well be one that ought to be incorporated into a new amendment. Unfortunately, the government has not yet put forward its amendments and we are extremely concerned about that.

I also like the point you have made about the regulated versus unregulated professions. I think that is one that ought to be looked at.

You have not addressed the question of capacity training. I would be very interested in knowing, first of all, what training dentists are required to undergo in terms of determination of capacity or competence of the patient, and indeed the allied dental industry, whether it is hygienists or dental technologists and so on who are involved in the delivery of dental care, what training they have in the determination of capacity, given that the way the act reads now, every person delivering care along the way would be making individual determinations of capacity.

**Dr Stein:** I certainly agree with you that every person along the way will be making that determination. As far as I understand, at the present time this is not something that is included in the curriculum of the dental school or dental hygiene or a dental assisting. It is something that will have to be addressed if this legislation is put into place. At this point in time I do not believe there is anything taught, certainly nothing to make the practitioners able, with any assuredness, to determine who has capacity within this situation or who is incapacitated.

1620

**Mrs Sullivan:** The other aspect to that, I suppose, is what parameters or teaching are presented to the dentist or the allied professions in terms of steps to be taken in determining who the substitute decision-maker is for the incompetent patient. None of that is done either.

**Mr J. Wilson:** Thank you for your presentation. To be perfectly frank with you, I am surprised how friendly your presentation is towards the legislation, because we have

had other dentists here who certainly do not like the legislation. I understand what you are doing, and that is to try and be as constructive as possible given that the government will go ahead with some form of legislation. It seems to me, though, that while the tone of the brief is friendly, as I say, your recommendations, really, for Bill 109 are fairly major when we get down to the legal text and may back up what the opposition has been saying, that we should be redrafting this legislation. We really feel that Bills 108 and 109 can go forward in some version, but not the one we are currently stuck with, so your recommendations there are helpful.

I did want to know whether you had any comments at all on Bill 74 and the Advocacy Act, though. That seemed to be a concern of some dentists who came forward and wondered, when they are required to call in an advocate, about the availability of advocates' training and the accountability. Do you have any thoughts about that?

**Mr Bromstein:** Apart from the obvious concern that the advocates were not being provided for children, which I gather was an oversight, I think there was no comment addressed to that because we had difficulty seeing, on a day-to-day basis in most dental offices, how the advocate really was going to function. A very small but not less important number of the Ontario populace will be affected who will be deemed incapable who would be in the non-children sector and would be treated generally by dentists. We understand how some of those people will need protection. This addressed the people who we thought perhaps were being encompassed but in fact did not need protection.

**Mr J. Wilson:** For the procedures you mention that perhaps the act should apply to, did you envision—you just simply say those procedures that would require treatment in hospital.

**Mr Bromstein:** For children.

**Mr J. Wilson:** For children. That is specifically for children. That is my answer to that one. You would sort of list those procedures in an addendum to the act or just whenever—I just think of myself when I was young. I had a choice between having a procedure done in a dental office or down the street in the hospital, depending on the availability, really, of the surgical room in the hospital.

**Mr Bromstein:** Those alternatives do not exist today the way they did at that time.

**Mr J. Wilson:** I am not that old.

**Mr Bromstein:** Changes occur frequently, though. There are only the most major oral surgical procedures, I think, that are generally performed in hospital, with some limited exceptions.

**Mr J. Wilson:** I see. So it is pretty cut and dried now.

**Mr Sterling:** I would just like to ask one question. Did you pick 16 years of age because of section 8, I think it is, which indicates that everybody under 16—or 16 and under; I am not certain which, but it does not matter for the purposes of the discussion—is considered incapable or incompetent? Is that why you picked 16?

**Mr Bromstein:** I think it was. Once again, it is a line that you have to draw somewhere. We understand that.

The draftspersons had drawn it at 16 and that did not seem unreasonable to the college, so we stuck to that line.

**Mr Sterling:** I think, from comments we have heard in the last couple of days, that the 16 is probably going to be removed. I would think the government might accept an amendment similar to the one that we introduced, which was that the common law be codified and that—does that change the age at all? One of the problems with what you are saying here is that people who are 16 and who are incompetent have protection, and people who are 15 do not. You face a problem whenever you draw an arbitrary age that way.

**Mr Bromstein:** I think we were trying to say in this presentation that in so far as children are concerned, dentistry does not have a problem today. The suggestion that we would live with the laws that now exist in so far as children are concerned would be one that would probably find favour with the college, but we used the 16, as you suggest, because 16 was in the legislation.

**Mr Wessinger:** Thank you for your presentation. One thing I would just like to make clear is that Bill 109 does not in any way change the principles of the existing common law, and I might run through some of your scenarios under the existing common law.

Scenario (a) is the 12-year-old child. Under the existing common law, you would right now have to determine whether that child was capable or not in determining whether to provide the treatment. If you determined the 12-year-old was capable to consent, then of course you could provide the treatment to the child. If you decided he was not capable, then of course you would look to the parent.

Second, with respect to the 14-year-old, it is the same question. You have to determine the question of capability right now. In other words, you would be breaking the law if you treated a 14-year-old child or a 12-year-old child whom you deemed to be capable, because they would have authority to make the decision with respect to their health care. That is the existing law.

With respect to item (c), that is probably one of your more difficult scenarios. I would suggest to you that even under the existing law it would be possible to argue that a child of eight would have enough capacity to decide whether he or she wanted to keep the tooth and could make a decision in that regard.

With respect to your item (d), I would clearly indicate that informed consent is a very important principle of this legislation, and I disagree with you on that point.

**The Chair:** Mr Bromstein, Dr Stein and Dr Beyers, on behalf of this committee I would like to thank you for taking the time out this afternoon and giving us your presentation.

#### SCHEDULING OF PRESENTERS

**The Chair:** Mr Winner.

**Mr Winner:** Am I introducing a new motion or are we still considering my motion made prior to the lunch-hour?

**Mr J. Wilson:** You just keep considering that motion.

**The Chair:** The previous motion was withdrawn.

**Mr Winninger:** Why do I not introduce a new motion, having withdrawn the previous motion? I still rely on the submissions I made before the luncheon recess; however, I am now moving that a letter go out over the signature of the clerk of this committee expressing the strong desire of the committee that this particular individual who is presently in Kingston and, if need be, the other individual at Mimico, be allowed to attend before the committee. That, I hope, will go a long way towards encouraging the health facility involved to make reasonable efforts to see that the individual can attend here and give a submission *viva voce*.

1630

**Mr Sterling:** Mr Chairman, after our meeting this morning I phoned Mr Harnick, who had no recollection of what was alleged this morning with regard to paying for a witness coming from afar or paying for people who were necessary to send with that witness to this hearing. I understand from what Mr Harnick told me that there was an agreement that we would look at paying for people who were unable to get here, who were vulnerable people in society, because of the nature of the bill, I guess, because of some correspondence received from a group in Ottawa which thought that was a necessity.

I would ask you, Mr Chairman, to obtain approval from the committee henceforth on behalf of our caucus for any of these kinds of expenditures dealing with these bills, because we do not or I do not—I assume Mr Wilson agrees with me—think we can justify the expenditure of two armed guards to bring this individual here, as I understand it would be necessary. We have given, in my view, this individual an opportunity to participate in these hearings in a reasonable and logical fashion. I think we have already done enough with regard to this particular individual to allow him to participate. He has been given options by you, I understand, Mr Chairman, and he has chosen not to exercise those options.

**Mr Malkowski:** Mr Chair, I would like to call the question for a vote.

**The Chair:** Might I make one recommendation before we put the question: that you change the signature of the clerk to the signature of the committee Chair?

**Mr Winninger:** I see. That would be acceptable.

**The Chair:** Okay. All those in favour of calling the question? All those opposed? You must vote. All those in favour of calling the question? All those opposed? Further debate? Seeing no further debate, all those in favour of Mr Winninger's motion? All those opposed?

Motion negatived.

**Mr Sterling:** Mr Chairman, I assume in your approach you are going to indicate you are not going to be paying for these two armed guards who are going to be necessary, because I had specifically requested that you have to come back to this committee for that kind of authorization.

**Mr Winninger:** Does that require another motion?

**The Chair:** Mr Sterling, being as the offer has already been made, maybe you would like to put forward a motion that we rescind the offer.

**Mr Sterling:** I move that we rescind the offer to pay for the two armed guards who I believe are necessary to bring this individual to Toronto as it is too costly to this Legislative Assembly and the taxpayers of Ontario.

**The Chair:** Mr Sterling moves that we rescind the offer to pay for the expenses of the two escorts. Discussion?

**Mr Winninger:** I would certainly oppose Mr Sterling's motion. I think that a great deal of public expense is involved in carrying on the important work of this committee, and while I do not know what it works out to on a daily basis, I imagine it is fairly significant. I think it is important to ensure that all members of the public enjoy the same rights to come before this committee that we accord sufficient moneys to enable this particular individual, who was previously scheduled to appear, to come. There is a third party presently standing in the way of his coming here, and I think payment of the expenses incurred by the health facility to bring him here would go a long way towards its cooperation.

**The Chair:** Further debate?

**Mr Sterling:** I see the need to spend taxpayers' money on things like food banks, in terms of providing adequate care for our sick and our needy, as a much, much higher priority than having a person appear here when he is given the opportunity to appear here by electronic means; he has been given the opportunity to present a written submission. If that is the NDP priority, so be it.

**The Chair:** Further discussion? Seeing no further discussion, all those in favour of Mr Sterling's motion? Opposed?

Motion negatived.

**The Chair:** Seeing no further business before this committee, this committee stands adjourned until 9:30 tomorrow morning.

The committee adjourned at 1636.

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**Also taking part / Autres participants et participantes:**

Spinks, Trudy, Ministry of Citizenship

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First Intersession, 35th Parliament

## Assemblée législative de l'Ontario

Première intersession, 35<sup>e</sup> législature

## Official Report of Debates (Hansard)

Thursday 12 March 1992

## Journal des débats (Hansard)

Le jeudi 12 mars 1992

### Standing committee on administration of justice

Advocacy Act, 1991,  
and companion legislation

### Comité permanent de l'administration de la justice

Loi de 1991 sur l'intervention  
et les projets de loi  
qui l'accompagnent

Chair: Mike Cooper  
Clerk: Lisa Freedman

Président : Mike Cooper  
Greffière : Lisa Freedman

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# LEGISLATIVE ASSEMBLY OF ONTARIO

## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

Thursday 12 March 1992

The committee met at 0952 in committee room 1.

### ADVOCACY ACT, 1991, AND COMPANION LEGISLATION LOI DE 1991 SUR L'INTERVENTION ET LES PROJETS DE LOI QUI L'ACCOMPAGNENT

Resuming consideration of Bill 7, An Act to amend the Powers of Attorney Act; Bill 8, An Act respecting Natural Death; Bill 74, An Act respecting the Provision of Advocacy Services to Vulnerable Persons / Projet de loi 74, Loi concernant la prestation de services d'intervenants en faveur des personnes vulnérables; Bill 108, An Act to provide for the making of Decisions on behalf of Adults concerning the Management of their Property and concerning their Personal Care / Projet de loi 108, Loi prévoyant la prise de décisions au nom d'adultes en ce qui concerne la gestion de leurs biens et le soin de leur personne; Bill 109, An Act respecting Consent to Treatment / Projet de loi 109, Loi concernant le consentement au traitement; and Bill 110, An Act to amend certain Statutes of Ontario consequent upon the enactment of the Consent to Treatment Act, 1991 and the Substitute Decisions Act, 1991 / Projet de loi 110, Loi modifiant certaines lois de l'Ontario par suite de l'adoption de la Loi de 1991 sur le consentement au traitement et de la Loi de 1991 sur la prise de décisions au nom d'autrui.

**The Chair:** I would like to make a small announcement before we start. To all the members: If anybody knows that anybody who is disabled or handicapped is coming in, all the disabled parking spots are at the back of the building now in the east court. Anybody giving directions from the MPPs or the ministry offices, please advise the people that the parking is there now and not in the front.

#### PERSONS UNITED FOR SELF-HELP, NORTHWEST

**The Chair:** I would like to call forward our first presenters, from the Persons United for Self-Help, Northwest. Good morning.

**Mr Magnusson:** Good morning.

**The Chair:** Just a reminder, you will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each caucus. As soon as you are comfortable, please identify yourself for the record and then proceed.

**Mr Magnusson:** Ladies and gentlemen, my name is Bob Magnusson. I represent the local grass-roots, cross-disability, self-help organization that is driven by consumers with disabilities. I come from the western frontier of Ontario, the last town in Ontario on the western border.

**Mr Poirier:** I am at the last town in the east.

**Mr Magnusson:** A long way between the two, yes. What has brought me here today is the Advocacy Act, Bill 74. Going through and over these bills, Bills 74, 108, 109 and 110, we have asked to have our input into this committee. We have concerns regarding the proposed bills.

One of our concerns is that the Advocacy Act, as it now reads, provides no guarantee that the advocacy services will be available in the same quality or degree to all people who fit the definition of vulnerable.

Another of our concerns is with dealing with the mechanism for provision of service with minimum qualifications of service and education standards for advocates, procedures and standards governing the provision of advocacy service. This education, while much needed, can soon be passed on to the education system. As we all know, I think, our education system is taxed and very cut back in the last while.

I represent here Persons United for Self-help, north-western Ontario. In my local town I represent the Physically Challenged Action Network, which is locally based, consumer-driven, people with disabilities. The purpose of PCAN, as our acronym is, is to facilitate collaboration among stakeholders in order to positively affect the full integration of people with disabilities in our Kenora area.

Picture individuals with disabilities having the skills and support to be responsible, to independently incorporate all aspects of community life into reality for each individual. The ability to advocate is identified as a crucial factor in achieving this vision.

Advocacy: Everyone in our society has the right to live life to the fullest, but many people with disabilities face barriers that prevent them from doing so. Perhaps they are denied access to facilities, transportation or programs. Perhaps the problem is attitudinal barriers. They can be as formidable as physical restraints. In some cases, the barriers may be self-imposed. Whatever the reason for the barrier, advocacy, the process of speaking up, can help the process to assist people with disabilities achieve meaningful change to conditions that adversely affect them.

A person with a disability, for a definition, is a person who is restricted in the type or amount of activity he or she can enjoy because of an intellectual, physical or emotional limitation. To empower people with disabilities is to give them the authority to effectively change the policies and the opportunities and attitudes that affect their quality of life.

We have been advocates, whether it is for crying infants or a lawyer pending a client's case. Advocacy is part of a person's effort to achieve a more desirable state, either personally or on behalf of another. Obviously, not all advocacy attempts are equally successful.

I have handed out the organizational structure of the self-help consumer movement of disabled people. This is a structure we have in the northwestern region. As it shows, it is only one of the six regions of Ontario. In the region

we have it broken down. My concern with being here and putting this forward to you is that there is an issue advocacy service that has been in effect and working, I could say, quite well since its inception in 1981. This is how it is set out. I would like to bring to the notice of this committee how this would fit in with individual advocacy as the Advocacy Act now is worded.

As this will show you, this goes from the grass-roots level of people in local towns, communities, coming to groups and associations like the Physically Challenged Action Network in each district. Each district has its own names for its organizations and groups, but we call ours PCAN.

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If you look at a flow chart, most people will go from the top down, will go from the provincial down to the regional, down to the local level. This is different in our concerns. Our concerns come from the bottom up to the provincial level and also go on past the provincial level to the federal level and also to the international level with Disabled Peoples' International.

In closing my remarks, the advocacy service should be well-established before an attempt to develop the legislation about decision-making. Only with the necessary support in place and working to the benefit of people with disabilities can we begin to know whether the perceived need for guardianship is in fact real.

**Mr Poirier:** Bob, you mentioned at the beginning that you feel there are no guarantees that the advocacy services will be available in the same quality or quantity as you have explained you have right now, which seems to be something very interesting. Could you elaborate, expand a bit on that? Also, are you able to point to specific areas of what is proposed right now that you feel could cause harm to the quality and quantity of service as you offer it right now?

**Mr Magnusson:** The quality of service I see through the education proposed in the legislation is a very good idea. I definitely agree with having well-educated people to stand up and voice opinions. I am not sure exactly how the quality of service will affect people in the northern regions in smaller communities and smaller towns. That is why I brought this up with the committee. Services accessible to everyone are hard to find, places in smaller towns and communities that are accessible. Buildings that are wheelchair-friendly often become wheelchair-hostile as soon as you walk through the door. This is one of my bigger concerns, that there is something past the Thunder Bay region of Ontario. People think that there is an expanse of almost 400 miles between Thunder Bay and where I live, and it still goes on to the border. Our region covers from White River to the Manitoba border, north and south.

**Mr Poirier:** Are your services on a voluntary basis, everybody?

**Mr Magnusson:** Everyone is on a voluntary basis.

**Mr Poirier:** No paid staff?

**Mr Magnusson:** No. Well, we do have a community coordinator in a regional resource centre. We now have a part-time paid staff. Locally is all voluntary.

**Mr Poirier:** Is there any type of training for your volunteers right now?

**Mr Magnusson:** Experience.

**Mr Poirier:** Okay. No doubt that is the best training of all.

**Mr Magnusson:** No, there is no training that I have been able to find, now speaking as a student of Confederation College at Lake of the Woods campus, to go into disability issues other than the third year of special ed student teacher.

**Mr Poirier:** How do you feel? Do you think that there is going to be a parallel group of advocates? How do you react or what do you understand from the legislation, that there will be a different group of government advocates that will parallel—

**Mr Magnusson:** That is what I see and that is my concern, that issue advocacy is in place and has been working for 10-odd years.

**Mr Poirier:** Do you feel that those proposed may be a competition or a duplication of service?

**Mr Magnusson:** I do not see how any advocacy could be of competition. But yes, I see that there could be worked into our plan some kind of formal structure or commission, something on that idea. I am not sure. I do not think we have the time today to go into how it could affect.

**Mr Poirier:** How much time do I have?

**The Chair:** As much as you like, just about.

**Mr Poirier:** Fair enough, thank you. If some formal training were available for government-appointed advocates, would you want you and your volunteers to be able to benefit from such formal training? Do you feel that could be helpful or what?

**Mr Magnusson:** I think we could almost be the trainers.

**Mr Poirier:** Okay. I like this kind of demonstration of confidence. We should all listen to this gentleman more carefully. I think the point you make is very important. Are there other aspects—how about Bill 109? You have talked almost exclusively about Bill 74, the Advocacy Act. Are there any other points from other bills you feel your group has a problem with?

**Mr Magnusson:** Yes. I have dealt mostly with Bill 74 because of the fact that I feel, as in my last statement, the advocacy service should be established well in advance of any kind of guardianship act or legislation, as I said, to perceive the need for a guardianship act and if it is really needed.

**Mr Poirier:** As for these guardianship acts and whatever, consent to treatment, are there specific points in there that can cause you and your group some problems?

**Mr Magnusson:** Yes. I think there are actually lots, but I cannot comment—

**Mr Poirier:** Right now. You are more than welcome. If you and your groups get together and look at it in more detail and you want to give us some feedback as to what you like or do not like, do not hesitate to let us know, because I think it is extremely important. I could go on, but I will leave my colleague some chances to ask Mr Magnusson some questions.

**Mr Carr:** First of all, I wanted to thank you for appearing here and also for a lot of the fine work I am sure a lot of your group does. The question I have is along the same line as the previous one. If this legislation goes through, I am wondering how you see your group fitting in. I guess it is very difficult to do that. One of the things that may happen is that you may be pushed aside, but there also could be the opportunity that some of the people who are doing the volunteer work would be the ones who would step forward. Just based on your best estimate, how do you see it working if the bill goes through?

**Mr Magnusson:** I see the need for our group will always be there, because this legislation only addresses the fact of vulnerable people. Not all people with disabilities are vulnerable. I can go into the horror stories locally of how even our municipal offices are not accessible to a person with a wheelchair. These kind of needs will—hopefully soon—eventually get dealt with and overcome, but I do not see how our group will be pushed aside or be in—I do not know how to say it—competing with what the Advocacy Act would do.

**Mr Carr:** What you seem to be saying is that it is a case of priorities. You see other areas as a priority, because what you talked about really was having some service, particularly in some of the smaller communities. What you are saying is we do not have those services and that is what we should be pushing, rather than spending time on this bill. In the overall scheme of things, is that basically what you are saying?

**Mr Magnusson:** There is definitely a need for basic services throughout all smaller communities where there are either no or very small parts of service, yes. This is the kind of thing I have tried to come and bring to the attention of this committee.

**Mr Carr:** With regard to that, I am interested in the process of how you have done that in the past, tried to get some of your messages forward and carried that. Is there anything else you have been doing? I am sure you have been working very hard in that regard and probably could tell us a number of committees you appeared before and on and so on, but maybe you could just enlighten us on how you see yourself pushing for that.

**Mr Magnusson:** From a very local level, we work on almost all the issues that relate to people with disabilities. Currently we are making presentations to the long-term care redirection, the employment equity commissioner. When she came to Thunder Bay I made a presentation. While I was in Toronto, I just got getting human rights enforced effectively and an appointment to make a presentation to the committee, totally all on a voluntary basis.

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**Mr Carr:** Sometimes I think we get tied down in thinking that we are not making very much progress, and maybe we are not, but I just want to say that we have moved ahead over the last little while. I wonder what your feelings were overall about the progress that has been made, particularly as it relates to your area. Is it slower than you would like? Do you see some movement? Maybe you could just give us an assessment of how you see it.

**Mr Magnusson:** I have followed the Advocacy Act very closely since it came out at first reading. Things have been very slow, especially carrying it down into smaller communities. I see the work we are doing and the funding definitely is not available. Our particular small local group worked on a community action fund of \$5,000 last year. It is not very much money for anyone to work on to open an office—all voluntary staff. It definitely needs a lot of work.

There has been progress made. As I pointed out to the Ombudsman in Kenora last week when she was there, unless you are among the top people with disabilities and have some mobility, you would not be able to get into her office. She said she would look into this. There are other facts, like provincial money being spent in our town on the library, for instance, instead of having as a priority services for people with disabilities. In the future there will be a contract to maybe put a ramp in the front door.

**Ms Carter:** You seem to have several concerns here. I hope eventually it will prove that things are going to work the way you want them to.

One concern you have seems to be the training of advocates. In the act as it is now that is not really set out; there are no guidelines for the training of advocates. That is because we are leaving it to the commission to make those decisions when it is set up, because we do not think that is something the government should decide. As you may know, the body that is going to choose the people on the commission is going to include people from all kinds of different categories as set out in section 15 of the act. I do not know whether you have looked at that.

**Mr Magnusson:** Yes, I have, very well.

**Ms Carter:** It does include all the different categories of consumers, which would give you people a chance to be part of that and then maybe to actually be on the commission when it is chosen. I hope you will, in fact, in that kind of way, get input into how the training is going to take place. I do not think the idea is to have people getting some kind of fancy certificate or doing fancy college courses. I think probably experience and so on is going to be taken into account. Do you have any ideas as to how that might work out?

**Mr Magnusson:** In speaking of section 15, in section 13 I see that this advisory committee would be only eight people and I do not see how—

**Ms Carter:** No.

**Mr Magnusson:** Clause 13(1)(a) says, “eight persons appointed by the minister, each having first been nominated by the organizations belonging to one of eight categories described in subsection 15(1).”

**Ms Carter:** No, it says at least 20 members.

**Mr Magnusson:** I have not seen that.

**Ms Carter:** Subsection 15(2), after listing all those categories, says—I am sorry. No. The organizations—

**Mr Magnusson:** The organizations must have 20 members.

**Ms Carter:** The organizations must have at least 20 people. Yes.

**Mr Magnusson:** In my town of Keewatin the population is only 2,500. Having 20 people with disabilities and working on a voluntary basis in a group could be a problem in that town. Not in our town, because we have a very active voice, but in other small towns I could see this being a problem.

As section 13 says this committee would only be set up with eight persons, it is a concern about how you can get a cross-section of Ontario out of eight people.

**Ms Carter:** No. There are additional people. It is eight appointed by the minister. Would counsel like to come in on that and clear up this point?

**Ms Spinks:** The appointments advisory committee will be composed of 10 people, eight nominated by the groups and two appointed by the minister.

**Ms Carter:** The point is that those people are going to help choose the actual commission and then the commission itself is going to look into the whole question of how advocates should be trained. There is nothing cut and dried about that, and you can still have input into how that is going to turn out.

**Mr Magnusson:** Yes.

**Ms Carter:** Do you see your group playing a role in the education process when the act comes into force?

**Mr Magnusson:** Oh, yes, definitely. In sitting with our local committee for skills development, we are looking at the projects of training the trainers. I definitely see how Persons United for Self-Help in Ontario and in the regions could fit into this, yes.

**Ms Carter:** That is how we want it to be. You also have concerns that existing volunteers are going to be set aside somehow. Again, I do not think that is something that is envisaged in the act. We want to see existing volunteers empowered by the legislation. The more formal, paid advocates hopefully will act as a resource to help those people be more effective in what they are already doing. Could you comment on that?

**Mr Magnusson:** Yes. In going over the act, I see the place for the volunteer, but it would also encompass the rules and regulations you would put on the provincial advocates. On an individual basis, I see how this could be very good. On the issue basis of how we work now, I do not think conflict of interest or the Freedom of Information and Protection of Privacy Act would come into it, because we do not deal with individual people; we deal with individual issues, housing issues or transportation issues.

**Ms Carter:** Of course that comes into advocacy too. The advocate is going to have two functions. One is to listen to individual people who are vulnerable or not being treated right and just carry out their wishes, not force anything upon them at all. The other thing they can do is, if they find that a lot of people have the same problems because of the way the system works, they can do things to change the system.

**Mr Magnusson:** Yes. I have found that in making briefs to these kinds of committees and commissions, they do help. There is definitely a place for a voice.

**Ms Carter:** Okay. Thank you.

**The Chair:** Mr Magnusson, on behalf of this committee, I would like to thank you for taking the time out and coming down this morning and giving us your presentation.

**Mr Magnusson:** Thank you.

1020

#### ONTARIO PSYCHOLOGICAL ASSOCIATION

**The Chair:** I would like to call forward our next presenters, from the Ontario Psychological Association. Good morning. Just to remind you, you will be given a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, please identify yourselves for the record and then proceed.

**Dr Nielson:** I am Dr Warren Nielson, president-elect of the Ontario Psychological Association. I am also the former chair of OPA's legislation committee and presently chief of psychology at University Hospital in London. With me is Dr Ruth Berman, executive director of our association.

The Ontario Psychological Association is the voluntary organization representing the profession of psychology in Ontario. Our membership of approximately 1,400 includes psychologists, psychometrists and graduate students in psychology.

We are pleased to appear before the committee this morning to comment on Bills 108, 109 and 74. The OPA has followed the development of these bills with great interest and regards them as important legislation for enhancing and protecting the rights of Ontario citizens.

First I would like to turn to Bill 109. The proposed act is an attempt to deal in a comprehensive manner with issues of consent with respect to all forms of health care treatment. We agree that the act should apply to all regulated health practitioners and across all health care settings. We strongly support the principle of consent as a requirement for health care and are pleased to see that an intent of the legislation is to codify the elements of consent and define the term "informed consent." The OPA is pleased that the legislation recognizes that capacity is not a global concept and specifies that consent must be related to specific treatments.

Bill 109 sets out the procedures to be followed by substitute decision-makers on behalf of incapable individuals and provides direction to health care practitioners in clarifying who may be entitled to act on another's behalf. The proposed act also defines the provisions under which emergency treatment may occur in the absence of consent. Finally, this bill establishes a Consent and Capacity Review Board, which has the power to review findings of incapacity, appoint representatives for incapable individuals give direction to substitute decision-makers, as well as give direction with respect to instructions and wishes that are unclear.

While we support the above provisions and their intent, there are some aspects of this bill that we find to be poorly delineated or of some concern.

The first of these is the definition of "treatment." Subsection 1(1) includes diagnostic procedures under the definition of "treatment." Some psychodiagnostic assessment procedures are conducted for the express purpose of determining an individual's mental or cognitive capacities—for

example, a neuropsychological evaluation of a head-injured client. Obtaining informed consent for such procedures requires that some judgement of capacity be made prior to test administration. In many instances, because of the nature of the patient's presenting problem, a judgement of incapacity is difficult to make prior to and in the absence of the testing procedure. Is it the intent of the legislation to apply the same provisions for consent in circumstances where the purpose of the treatment is to determine mental capacity?

2. Subsection 5(3) allows for consent to be either expressed or implied. In its current form, the legislation offers no definition of the circumstances under which consent may be implied. In the absence of a definition, both practitioners and patients will be left on their own to determine a definition of the term "implied." Moreover, situations may occur where practitioners and patients may have different interpretations of what is intended. When such circumstances arise, how will these differences be resolved?

3. Subsection 5(2) outlines the definition of "informed consent." As defined, it is unclear what the phrase "all the information about the treatment" means. In the course of psychological practice, psychologists would be obliged to inform their patients about "alternative courses of action and the material effects, risks and side-effects" of treatments or diagnostic procedures. However, many of the diagnostic instruments used by psychologists require a degree of naïveté on the part of the patient. If they are required to provide all the information about the treatment, many of the diagnostic procedures in use may be invalidated, and hence useless for their purpose. Clear guidelines as to the amount of information to be made available to patients should be provided within the legislation. If full disclosure is required under the legislation, we would suggest some form of exemption in the case of psychodiagnostic procedures.

Another issue that should be considered in the matter of informed consent involves the patients' right to choose how much information they would like given to them. While we agree that in most circumstances practitioners have an obligation to offer patients all the information about the treatment, we also believe patients should have the right to decline detailed information if they so choose. For example, a patient who is about to undergo a painful or emotionally distressing medical procedure may elect to decline detailed information in order to better cope with the circumstances. Compelling an individual to receive complete information in such circumstances may place him at higher risk for poor treatment outcome and adverse psychological sequelae.

4. Sections 32 through 42 establish the Consent and Capacity Review Board, whose purpose is to hear appeals and consider requests for reviews of status with respect to incapacity. We believe that given the particular expertise of psychologists in assessing mental competencies, consideration should be given to the appointment of a psychologist to this board and, as well, for the inclusion of psychologists among those with expertise in evaluating capacity for the purpose of serving on panels, as per subsection 35(3).

5. Under section 45, the Lieutenant Governor in Council may make regulations prescribing forms for the purpose of subsection 5(4), may prescribe criteria to be applied and

standards and procedures to be followed in determining capacity. The OPA would encourage that in both circumstances the regulatory bodies for those health practitioners who might be affected under section 45 be consulted during drafting of these regulations. The respective professional regulatory bodies are responsible under statute for setting and monitoring adherence to standards of practice for members of their professions. Their involvement in the development of these regulations is therefore essential.

6. We would encourage that consideration be given to including in the definition of "informed consent" a requirement that the patient be advised about the limits of confidentiality with respect to the treatment in question. For example, patients should be aware that the confidential nature of their health record may be limited by other statutory requirements, such as in the case of child abuse or precedents in common law, such as the duty to warn.

7. Psychologists provide services in a variety of treatment settings that are governed under different statutes. Subsection 37(2) makes reference only to the Mental Health Act and Child and Family Services Act and excludes, for example, the Public Hospitals Act and the Education Act, as neither of these statutes currently has provisions regarding withholding of records for persons with mental disorders. As a result, patients treated by psychologists in facilities governed by, for example, the Mental Health Act will have differential access to their records as compared to individuals seen by a psychologist in a facility as defined under the Public Hospitals Act.

We believe that this inconsistency should be addressed by making the necessary legislative amendments to ensure that subsection 37(2) is applied equally to all individuals affected. Similarly, subsection 39(2) should be amended to require that all clinical records be returned to their point of origin, irrespective of whether or not that facility is governed under subsection 35(1) of the Mental Health Act.

Regarding Bill 108, the OPA supports the intent of Bill 108 and endorses the concept of enabling competent individuals to predetermine the manner in which they shall be cared for and their property managed in the event they should become incapacitated. This principle is consistent with the values and goals of professional psychology, which support the development of individuals and their capacity for autonomy and self-determination.

Bill 108 also attempts to preserve the rights of individuals whose competence may be in question such that their interests and wellbeing are safeguarded. In addition, provisions have been made for designation of health care practitioners who would be responsible for determining an individual's mental capacity with respect to his ability to care for himself and manage his property.

Unique to the practice of psychology is the availability of scientifically based, objective measures of cognitive and social competency. Judgements of this nature form the core of psychologists' diagnostic expertise and are central to our clinical practice. These skills are widely recognized within the health care community and have been recently recognized within the new Health Professions Act. The contributions of psychologists as diagnosticians have already been acknowledged in statutes such as the Courts of Justice

Act, the Evidence Act and the Automobile Insurance Rates Control Act. Requests for such diagnostic opinions are commonly made to psychologists by physicians, including such specialists as psychiatrists and neurologists.

Psychologists are concerned with those sections of Bill 108 which include references to the definition, training and regulation of assessors of competency. In this regard, the Ontario Psychological Association is in full support of the recommendations for amendment previously submitted to you by the Ontario Board of Examiners in Psychology. Thus we wish to draw your attention to a number of issues which we feel are of particular significance.

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In the interest of public protection we would recommend that those individuals to be designated assessors within the regulations be selected from among those professions regulated under the new health disciplines legislation. The determination of mental incapacity is, for all intents and purposes, a diagnostic act. Therefore, we propose that the selection of assessors be from among those service providers currently recognized in the RHPA as authorized to diagnose mental disorders and diseases. This would currently limit the definition of assessors to specific medical specialties and psychology. In this manner, public protection could be ensured through the regulatory mechanisms and quality assurance programs of colleges under the RHPA.

At this time, some sections of the bill explicitly name only physicians as assessors. As has been previously recommended by two government-sponsored inquiries—the Fram commission and the Weisstub inquiry—we strongly encourage the inclusion of psychologists as among those qualified to perform assessments of capacity. Psychologists are historically recognized as principally responsible for the development and application of scientifically based instruments for measurement of cognitive and social capacity. In light of this special expertise, it is surprising that the bill fails to specifically name psychologists as assessors. We recommend that both psychologists and physicians be identified as assessors of capacity in this legislation.

A number of amendments that we recommend are before you. We also recommend, as did the Ontario Board of Examiners in Psychology, that all competency determinations, whether positive or negative, should be documented and forwarded to the public guardian and trustee. The legislation as drafted has no requirement for the reporting of negative findings. This oversight may lead to the phenomenon of assessor shopping for the purposes of eventually securing a confirmation of incapacity. The rendering of a negative finding may be important in particular cases and the failure to document such information may impact on the status of some individuals where such information may bear on important decisions.

Bill 74: The OPA supports the principle of ensuring that vulnerable persons have access to advocacy services in cases where they have difficulty expressing or acting on their wishes or in ascertaining or exercising their rights. We agree that in some circumstances there may be a need and an important role for an official advocate. However, we do not believe that such intervention is warranted in all

cases, and propose a more restricted and better-delineated scope of application for formal advocacy services.

Subsection 3(1) of Bill 74 states that the act applies to vulnerable persons who are “16 years of age or older,” and subsection 10(7) of Bill 109 indicates that similar provisions would apply in circumstances in which an individual who is less than 16 years old demonstrates “a wish to give or refuse consent to the treatment on his or her own behalf.” If it is the intent of the legislation to apply in all such cases, we are concerned that the role traditionally reserved for family members, legal guardians or other care givers, will be significantly reduced, if not eliminated entirely. Moreover, it is difficult for us to support, in a time of economic restraint, the introduction of an administratively complex and very expensive bureaucratic system.

We wish to express as well serious concerns regarding the wisdom of providing a system which could inadvertently harm those individuals the legislation is meant to protect. Bill 74 sets out requirements for the use of advocates in a manner that could potentially interfere with the provision of essential, effective and timely care, possibly resulting in a loss of life. Thus, we encourage a re-examination of Bill 74 in light of these concerns. We understand and respect the principles that have guided the development of this bill. However, we are concerned that this legislation may not truly meet the needs of our vulnerable populations, may obstruct the capacity of health care providers in their efforts to provide efficient and effective service, and will deny family members and care givers the right to fulfil their traditional role as advocates. We thank you for your attention and would be pleased to answer any questions you might have.

**The Chair:** Thank you. Each caucus will have about five minutes for questions.

**Mr Poirier:** Thank you for coming forward. It is an interesting perspective you have as health care providers, if I may refer to you as this. I think I can, unless you object.

**Dr Nielson:** Absolutely.

**Mr Poirier:** You are not physicians, obviously, but I am glad that—and I think your request that psychologists be considered, especially as assessors—if you guys cannot do it, I am not going to go to my mechanic, I guess, to get it done, really. So I hope the PA and the government will be sensitive to that request.

I would have thought, if I may give a constructive criticism, that you would have gone maybe into more detail as to what particular aspect caused you a problem. On your second-last page, when you look at Bill 74—and I think the same request I can make also for the other bills—“serious concerns regarding the wisdom of providing a system which could inadvertently harm those individuals the legislation is meant to protect.” The same with consent to treatment—obviously people are brought to you or come to you to get an assessment of their mental capacity, for example. Fair enough. But other health care providers do not have your training to be able to make that assessment, and yet before they can do anything they are supposed to do to give treatment, whether in an emergency situation or not, they must be able to assess what their mental capacity is.

So the irony of it all is that non-psychologists have to be able to assess mental capacity as to whether they are capable or not, whereas you people seem to claim here that you need to go through the process before you can state, "You're vulnerable," or "You're incapable," or not. I find that an interesting comparison between your group and other health care giver groups.

Some people who have come from other groups also state, "Well, we don't have the training, yet maybe you expect us to be able to look at the person and right away say, 'No, I can't treat you because I suspect that you're vulnerable and incapable.'" Any comments on that? I find that interesting.

**Dr Neilson:** We see this process of looking at somebody's mental capacity as a very complex one that requires a fair amount of training if somebody is going to be doing it in an effective and competent manner. So that is probably why our perspective is a little bit different than other people's. It is an area that is probably, as I was saying, sort of a core element of what a psychologist does.

**Mr Poirier:** If I were to be an assessor, I would rather be in your shoes with your baggage of knowledge and capabilities to be able to judge, rather than the other health care providers who are going to have to pass the same type of judgement you will and yet not be as equipped as you are to do it.

**Dr Berman:** I think that many health care providers, on the basis of their knowledge and experience, can make some initial judgement on the basis of a patient's presentation and perhaps generate a hypothesis about that individual being capable or incapable.

**Mr Poirier:** Of course.

**Dr Berman:** Formal psychological assessment, though, looks at a variety of cognitive and mental functions in a very specific kind of way, in a way that cannot be determined or evaluated on the basis of simply a clinical interview.

**Mr Poirier:** I would have thought you would have expanded more on Bill 109. I would have really thought that. Not saying that it does not affect you or your profession, but there must be some other points. If I am basing myself on the presentations of other groups of health care providers, I would have thought that, of all people, you might have been able to expand even more on some of the problems that Bill 109 could end up causing you as a profession, as individuals in your profession.

Do I exaggerate? How do you feel about this statement? Do you feel there are other points you could evolve, or is that it? I know this sounds like a leading question. But just tell me, "No, you're way overboard," if you think so.

**Dr Berman:** The purpose of the presentation was to try and highlight some of the things we saw as sort of central for us. Your comment about other health care providers coming forward and saying that Bill 109 puts them in some difficulty because they are being asked to make a judgement about somebody's capacity without having any training: It is difficult for us to speak on behalf of other health care providers.

**Mr Poirier:** Of course.

**Dr Berman:** The legislation seems to allow for an assessment of capacity to be made specific to the particular treatment that the individual is being considered for. To some extent, while psychologists can assess capacity in a general way—for example, I am not a speech pathologist and I believe that a speech pathologist would be able to make some initial judgement as to whether that individual would be able to grant consent to speech therapy.

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**Mr J. Wilson:** Thank you very much for your presentation. Unlike my colleague Mr Ironside—excuse me, Mr Poirier—I felt it was a very good presentation, an excellent addendum to what we have heard before. I just thought I would liven things up this morning. I like to do that once in a while.

Have you seen the PC amendments that have been put forward?

**Dr Berman:** Yes.

**Mr J. Wilson:** We had asked the clerk to make sure that groups had those. I think we are very close to agreement, if not right on, with the amendment we put forward with respect to definition of treatment and, second, with respect to age 16 and competency, and we are encouraging the government to bring forward similar amendments so we can ensure they will get passed.

**Mr Poirier:** Once they start working on them, right?

**Mr J. Wilson:** That is a good point.

I was very interested to note one point I do not think I had heard before: the patient's right to decline information. I thought that whole section there was quite well done, and also the pointing out to us—because we are not psychologists, or I do not have that training, that is for sure—that certain diagnostic instruments require a degree of naïveté, and I understand where you are coming from there.

I do want to ask you a question about Bill 74, because I think your presentation follows very closely what I and my colleagues have been saying, that we are not very happy at all with Bill 74 and have asked the government to redraft that and take a step back and see if we cannot come up with a better system, perhaps less costly, and you mentioned that in your presentation. But we think with some major amendments to Bills 109 and 108 we can probably live with that legislation. The government has been going in the opposite direction. They want to push Bill 74 and rumours are they are—well, I do not know what they are going to do with Bills 108 and 109.

We presently do have advocates in the psychiatric hospitals. Can you tell me your experience with that, and would our resources perhaps be better spent on enhancing that advocacy system that exists? I will just say that much of the testimony we have had is that there is the real need in the area of mental health and perhaps there is not the need in the day-to-day health care settings of regular hospitals for advocacy services. Perhaps you could comment, please.

**Dr Berman:** I would agree with you. There are some advocacy services that are currently available. I think our

preference would be to see those services enhanced and reinforced.

I guess, from my point of view, there is a certain message that is being delivered by this legislation, and that is that in the health care field there is a mistrust of service providers and there is a need to protect patients from potential abuse by health care providers.

In addition to reinforcing existing advocacy service, I think we should also reinforce greater education for health care providers, and I think the new Regulated Health Professions Act, with its emphasis on quality assurance and adherence to standards and accountability, will serve as well to protect individual rights. I think part of the onus for this rests with service providers in educating them about patients' rights and making sure that adherence to standards and ethical principles is followed.

**Mr Winner:** Thank you for coming today. I certainly enjoyed your presentation. I am just going to direct one question to Bill 108 and let my colleagues address your other concerns.

A number of professional bodies, like yourself, have come forward and suggested that just because one is a physician does not mean that one has the necessary background, training and knowledge to conduct assessments. I just wonder if you would be satisfied were the word "physician" to be removed in section 50 and section 70 and some of the other related sections rather than adding in a list of all those professions that feel they have equal knowledge, background and training to conduct assessments.

**Dr Berman:** Some form of definition of who can conduct competency assessments has to appear either in the act or in the regulations. You either include the other groups in the act or you take out who is there now in the act and define them in the regulations. The legislation is inconsistent. At one point it says "assessor" will be defined in the regulations but at other places it makes reference to physicians, so it presupposes. It should be either/or.

**Mr Winner:** I am just asking you whether deleting the word "physician" would satisfy your concern. Then assessors would be prescribed by regulation.

**Dr Nielson:** Yes.

**Mr Winner:** Thank you.

**Mr Wessinger:** Thank you very much for your presentation. I enjoyed it and I also thought it took a very constructive approach with respect to Bill 109. I would like to ask you a question with respect to your criticism of all the information about treatment. As you know, that should be read in other words, "that a reasonable person in the same circumstances would require in order to make a decision," so it is qualifying by a reasonable test.

Would you feel more comfortable with that section if the word "all" were removed and it just said "the information"?

**Dr Berman:** Given our comments about diagnostic tests used by psychologists, I think I would be more comfortable with it.

**Mr Wessinger:** Fine. The other thing I would just like to comment on is your comments with respect to the matter of confidentiality. I must indicate to you that our ministry

agrees with you in that regard. We believe this should be dealt with separately, and certainly it is the intention to deal with it in the future under health care information and the privacy act.

**Ms Akande:** I was going to ask about assessment, but I think that has been well covered. One question constantly nags at me, though, that has been brought up by several groups: advocacy—the feeling that the system that is in place now is sufficient to care for the needs of patients. My concern is this: Certainly there is a great deal of information out there that says, "In spite of the fact that there are systems in place, in spite of the fact that the medical and other professions have the best intentions, in spite of the fact that most people do the right thing, there are those who in fact have suffered." We have heard from some of those people. In view of that need, we have tried to design as broad a system as possible. Timeliness, getting the right treatment to the right person on time, is of course always a concern. In spite of what I have said and what you already know, are you of the opinion that this act is unnecessary?

**Dr Nielson:** I guess we feel the problems that led to the writing of this act could be addressed in a different way. I think the problems arose partly from individual problems with regard to specific health professions, and that with the new Regulated Health Professions Act these sorts of questions could be addressed in the context of the regulatory bodies. They have the power now, I think, to make changes so that these sorts of problems do not arise nearly as frequently as they have in the past. I think it is also what Dr Berman said about education of professionals. I think that is the real problem.

**Ms Akande:** Of course education does take time, does it not?

**Dr Nielson:** Yes.

**The Chair:** Dr Nielson and Dr Berman, on behalf of this committee I would like to thank you for taking the time out this morning and bringing us your presentation.

1050

#### ONTARIO MEDICAL ASSOCIATION

**The Chair:** I would like to call forward our next presenters, from the Ontario Medical Association. Good morning. I remind you that you will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, please identify yourselves for the record and then proceed.

**Dr Warrack:** I am Ian Warrack. I am a GP from Vanier and a member of the Ontario Medical Association's board of directors. First, I would like to thank the committee for giving us the opportunity to speak today. On my right is Ted Boadway, a physician and director of health policy at the OMA, and on my left is Barb LeBlanc, who is also from the OMA staff and is the brains behind our response.

**Ms LeBlanc:** Blame it on me. Fine.

**Dr Warrack:** The OMA represents the province's 20,000 physicians and has as its mission: "to serve the

medical profession and the people of Ontario in the pursuit of good health and excellence in health care." Examining proposed legislation such as this is one of the ways we fulfil that mission.

As I understand it, the primary purpose of these three pieces of legislation is to enhance and protect the dignity, rights and autonomy of vulnerable adults, particularly in matters pertaining to health care. The OMA has some serious concerns about the ability of this legislation to achieve its intended purpose. In addition, I believe this legislation will have some unintended consequences which will in fact result in poorer quality of life for some of the people it is attempting to assist because of delays to health care. We will use some case examples to illustrate our concerns and to demonstrate what this legislation will mean for patients.

The legislation we have before us is, quite simply, not workable. I believe this has happened because the government did not anticipate the impact of this legislation in the real world when it wrote it. The OMA has been working for a number of months to convey this message to government, but we do not feel confident we have been understood. We will highlight some of the key issues of concern from a physician perspective. Our comments will focus primarily on the relationship between advocacy and consent to treatment, since that is the area that will have the greatest impact on the delivery of health services.

This should not be taken to mean that we do not have concerns about the other acts; we do. In fact, the OMA believes that both the public and health care practitioners would benefit from the introduction of good legislation on consent and substitute decision-making. We also believe that protection for vulnerable people who are at risk of harm is important. We do not, however, support a fast-tracking of the Advocacy Act as standalone legislation.

**Dr Boadway:** As Dr Warrack has just said, this legislation, although founded on very laudable intentions, is seriously flawed. This has occurred at least partly as a result of the process that took place during the initial drafting stages. If one looks at modern management theory that is extant in the world, it has become clear over the past 20 years or so that in order to make a system work, whether this system is building cars or is a health care system, it is essential to have input from all levels: consumers, management and line workers. In this case, government recognized only part of the equation. The legislation we have before us reflects a significant appreciation of the consumer perspective, and that is not surprising since a fair amount of consultation apparently occurred between government and consumer groups during the drafting process.

Where the legislation breaks down, however, is at the point of implementation. This is due to the fact the government failed to consult with the line workers during the drafting stage. It is difficult, taxing and detailed work—painstaking work—that we are a part of. You will notice that in our appendix we have many constructive procedural recommendations in that regard. In this case, however, the line workers are the providers of health care services, and at some level we should have tested the practicability of the proposed system.

**Dr Warrack:** One of the most serious consequences resulting from government's lack of understanding about the actual delivery of care is the implicit notion that treatment delays are not harmful. That is quite simply not so. To illustrate, let me use an example.

An elderly woman who is living in her own home is capable to manage her own affairs. As her GP, I get a call from her daughter who has stopped by for a visit, saying that her mum has become confused. There is no apparent reason for this. I visit her and I suspect that there is an underlying physical problem. It is a very common problem in general practice, particularly when you are dealing with the elderly. However, I cannot be certain, because there are no immediate apparent physical symptoms and there are a number of possibilities that it could be. It could be a urine infection or it could be focal pneumonia. She could even have a minor stroke.

Since her confusion alone is not sufficient grounds to invoke the emergency provisions of the act, I would simply have to advise her that I consider her incapable and contact an advocate to meet with her. I cannot provide any treatment during that period. I cannot even take blood to determine whether there is an infection.

The problem here is that the elderly tend to deteriorate very quickly when faced with an even relatively minor physical insult, and that means if the woman is suffering from pneumonia, the delay in starting antibiotics could cause irreversible damage or even kill her. This is inhumane, and what you have done is develop legislation that will cause a decline in the quality of care available to incapable persons.

**Dr Boadway:** This legislation, in essence, invites system failure by asking physicians and other health care providers to do things they are not likely ever to be capable of doing, quite frankly. For example, an onus is placed on health care practitioners to ascertain which instruction to act upon in a treatment situation. Among the possibilities to sort through are validated powers of attorney, non-validated powers of attorney, oral wishes expressed subsequent to the power of attorney as relayed by a third party, instructions from family members as well as the present wishes of the incapable person. Physicians, I can tell you, are unlikely ever to master all the legalities involved in ascertaining what constitutes a reliable wish. The legislation must make it much clearer. This is especially important since physicians will be held legally liable for failure to comply with the requirements of the act and will be open to complaint and civil liability for the care they provide.

This, by the way, is only one example. There are other complex lists involved in the legislation which will be required for physicians and other health care workers to master. The problem is that health care workers are not lawyers, and even our lawyers are having difficulty explaining to us just how it will work.

**Dr Warrack:** One of the areas of major concern for physicians concerns the sections of the act relating to emergency services. It appears that government is attempting to provide some opportunity for prompt action in the event of dire circumstances. However, the reality of emergency care does not conform to the tidy perimeters outlined

in the legislation. The notion that serious consequence will occur within 12 hours is completely arbitrary and has no practical basis. In addition, the reporting requirements following the provision of emergency treatment are absurd. Again, let me use another example to illustrate.

A young man comes into the emergency department following a motor vehicle accident. He appears to have superficial injuries, a few cuts and scrapes, but he is dazed and not quite lucid. I must therefore contact an advocate before proceeding with treatment. It is important to realize that the definition of "treatment" under the act includes anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose. This means I cannot run any tests on him or do a physical examination. What if he was suffering from pneumothorax, a punctured lung? Although there would be no outward signs of a problem, he could die very suddenly within the hour, and this would happen because I had not been able to listen to his chest with a stethoscope, hear the air escaping, and insert a chest tube. This is the reality of this legislation.

**Dr Boadway:** Now that is a case where a physician, faced with a patient, cannot know there is an emergency developing but could easily ascertain if he could do a simple examination. They cannot know. It is not a matter of making a decision.

What would happen if you had a situation so clear-cut that you could invoke the emergency provisions? Imagine another motor vehicle accident where a young woman is hit by a truck on a highway in northern Ontario. She is taken by ambulance to the local hospital and met by the physician on duty, a family doctor with an interest in emergency medicine and two duty nurses. The ambulance service has alerted the hospital ahead of time and they are ready for her arrival.

It is immediately clear that the woman meets the emergency criteria under the act. She is bleeding profusely, has a number of broken bones, distinct evidence of internal injuries and is not conscious. It is possible that she has a significant head injury. The hospital, however, is not equipped to handle this type of emergency, so an effort is made to stabilize the woman's condition so that she can survive the transfer to a larger hospital. Arrangements are made and she is flown to Sudbury, the nearest specialty centre, by air ambulance.

When she arrives, a team is assembled and waiting. This team includes a physician, several perhaps—internal medicine specialist, orthopaedic surgeon and neurology have to be assembled. You have to have a specialist nursing team, radiologists have to be available, radiology technicians, laboratory technicians, and all of these have to be available to see the patient quickly. After each of these health care professionals has contributed to the life-saving effort, they will be required to notify the public guardian and trustee. In a case like this, there could be as many as 30 or more individuals, as a very realistic estimate, of the number who must report to the public guardian and trustee because each health care practitioner who administers treatment must. This would include all the hospital personnel in both hospitals plus the transfer people. We have quite serious concerns about whose needs are being met

here, just how much work is involved and what people will do with the confetti so generated.

1100

**Dr Warrack:** These examples demonstrate not only the problems with the emergency provision of the act but also the difficulties that are likely to occur due to the very broad definition of "treatment" which is used.

As drafted, this legislation would not only hinder physicians in making timely diagnoses; it would also affect many other health professionals in their ability to deliver care. For example, a nurse could not change a dressing, take a temperature or blood pressure. They are all simple procedures but crucial for care.

Many of these problems are the result of government attempting to transpose the framework for the mental health system on to acute care medicine. I am concerned that the proponents of this system cannot see the differences.

The last specific area that we would like to address is the age presumptions under the Consent Act. I understand that several other groups have already expressed their concerns about this, so I will not go into it in detail, but I will simply note that although I realize that the age presumptions, as written, do not preclude an adolescent from seeking health care independent of his or her parents, there is a tremendous concern that physicians and teenagers will misunderstand this clause, with negative results.

**Dr Boadway:** A second important point we will make briefly relating to children should also be mentioned. We hope that the clause permitting a young child to make treatment decisions is reviewed; it will have to be, quite frankly. I understand from the minister's comments in the press that there was never an intention to permit youngsters to refuse inoculations. It is, however, the reality of the present legislation, and we know it will have to be addressed.

**Dr Warrack:** To close, I would like to return to the question of implementation. The system that is proposed is complex, unwieldy and expensive. The legislation will have to be understood by all kinds of people not normally accustomed to interpreting legislation: doctors, other health care workers, families and the general public. I am not all that confident that will be possible.

The proposed system will require a significant number of advocates and assessors throughout the province. In addition, the success of a centralized public guardian and trustee office will be dependent upon its ability to process huge quantities of information effectively and efficiently, and that means a sophisticated computer system will be required, one that can be accessed from around the province.

**Dr Boadway:** Looking specifically at the delivery of medical care, it is clear that additional visits to doctors will be required. You had a very nice graphic demonstration brought to you by Dr Gordon, whom I thought did it better than I could, so we will just leave it with that. The initial visit and return visit following the meeting with the advocate will be often just *de rigueur*.

It can also be expected that specialists' consultations for competency assessments will escalate significantly. I predict that you will have a blip in the utilization factor

when this legislation is brought in, and at a time when utilization is under severe attack from within government and without. To put in something which will cause an increase seems to me to be counterproductive at this point.

The Ontario Medical Association is troubled that government plans to forge ahead with plans to create this layer of bureaucracy and increased utilization, and at the same time it is of marginal benefit when we and many others are working diligently to get the system costs under control.

In addition to the hard costs, it is also important to look at the soft costs of the system, those that cannot be readily quantified. Increased waiting times in emergency departments, prolonged pain and suffering for patients, unwanted intrusions into people's lives and disenfranchisement of families are just a few.

A cost-benefit analysis of the impact of this legislation is required before proceeding with implementation. How much is this really going to cost?

**Dr Warrack:** The OMA recognizes that the current system needs improvement. However, the legislation proposed to address the concerns would create more problems than it would solve, and at considerably increased cost. There is a need to better protect the vulnerable in our society and to promote autonomy where possible, there is a need to clarify the rules around substitute decision-making and advanced directives, and there is definitely a need to develop clear processes for the giving of consent. Unfortunately the legislation before us not only fails to achieve those goals; it would make the current system, although not perfect, completely unworkable.

The OMA respectfully suggests that this legislation be withdrawn and reconsidered, starting with a new consultation process, one that incorporates input received from not only patient rights and interest groups but also families, health care providers and other relevant stakeholders. Thank you very much, and we would now be pleased to take any questions on any of the three acts.

**The Chair:** Each caucus will be allowed five minutes.

**Mr Poirier:** Thank you very much for taking the time and especially for supplying a very exhaustive list of proposals. Obviously you are quite correct: We only need to try to put ourselves in your shoes, especially in an emergency situation. It becomes the Grand Canyon between the theoretical principle of this and the practical application, and I think you, as health care providers, are best placed to understand that. The gap is just too unrealistic. With the cost of all this, I think it is going to be the Treasurer who is going to tell the people there is no way we can afford to do this.

If each of the health care providers—as you say, 30 doctors have to work on one particular patient after a particular accident—will have to contact the public trustee and guardian, thank God my hero is Monty Python. If I did not have Monty Python, how the hell could I sit here and just go through this and say, “What are you trying to do?”

**Mr Winninger:** That is where your party policies come from, is it not?

**Mr Poirier:** That is right; exactly. The minister of silly walks, of course.

Thank you for bringing it forward. I can only hope that your specific observations and suggestions will be taken into account. If not, we in the opposition parties will gladly help them to remember and will remind them that between the theory and the practical application there is a hell of a gap.

**Mr Mancini:** First of all, let me thank you for your brief. I thought it was quite good and quite important to the work of this committee. Did I understand correctly that you stated there was no real consultation between the government and your organization?

**Ms LeBlanc:** I think the important thing is that during the initial drafting stages, particularly when it came to the Advocacy Act, we were unaware of the act until it reached second reading. In terms of what has happened subsequently we have had numerous meetings with each of the ministries involved, but during the drafting stages we were not involved at all.

**Mr Mancini:** You did not have any input or any opportunity to correct any errors before they were made?

**Ms LeBlanc:** We did not.

**Dr Boadway:** It depends how far back you go, too. If you go back far enough to some commissions that occurred, we were part of that. The absolute nub of making these things work is when it comes to the drafting. We have been involved in this before. It could be constructive.

**Mr Mancini:** I would think that if a new government is going to proceed with important legislation to assure itself that it has everyone's opinion and is doing things correctly it would want to consult an organization like OMA.

I understood you to say that health care in general is going to decline because of this legislation. You gave two or three examples. I am sure that if you were pressed you could probably give us 100 examples or maybe 1,000 examples. The job of the practitioner is to serve the individual who needs that service at that time. I wonder how it would be possible for the medical practitioners in this province to sit in their offices and say, “No, I can't serve you.” Are you actually going to be able to do that? If my young daughter ends up in your clinic or in your emergency room, would you actually not give service?

**Dr Warrack:** Following the act is certainly going to make giving treatment very difficult in a lot of circumstances: in institutions, whether they be long-term care institutions, hospitals or emergency departments, or whether it is in my office or in patients' homes. It is going to put in a lot of blocks on a lot of occasions. The way I handle patients is going to change, and that is obviously what is intended. For the vast majority of those patients the change will be for worse rather than for better.

**Dr Boadway:** One of the problems will be confusion. If health care workers do not have it straight in their minds—and I am pessimistic that they will—there will always be the pull of wanting to look after a sick patient—that is what their life endeavour is—and on the other hand worrying about their personal risk because their college is there and advocates are going to be watching. There always

will be that push-pull. Quite frankly, that is the wrong calculation to be making in many respects.

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**Mr J. Wilson:** Thank you for taking time out of your busy schedules to appear this morning. I want to ask a question about Bill 74. Although you did not touch on it too extensively in your oral presentation, on page 5 of your addendum to your submission you make specific comments. You talk about the role of advocates and you talk about the need for accountability of those advocates. Because I think the government is going to go ahead with Bill 74—that seems to be the promise out there to the vulnerable citizens community—we had better be somewhat constructive. Do you have any thoughts on how we can make the advocates more accountable? Right now there is no mechanism for complaint by a patient who may not be pleased with the work an advocate is doing on his or her behalf. There is also no mechanism for complaint by a member of the family or anyone else.

**Dr Boadway:** We have an idea. We are not sure how viable it is, but if you look at the Regulated Health Professions Act—and both you and I were involved in that in our respective roles—the principle followed there was that you are dealing with health care practitioners, in our case physicians, who are considered to be a powerful group with an important job. Although there is self-governance, that is too important to be left to the profession alone. Therefore there should be a very strong, independent input into this from the public. It should not be left to something like the OMA, that is sort of the champion of physicians, or their advocate, whatever you want, to do that. So it was not left to us to do it.

In this particular case, the Advocacy Commission is going to be the employer and the champion of advocates, as far as we can figure out. That is not the person whom, if a member of the public wanted to complain, they should complain to, any more than they would expect to complain to the OMA, nor, if a health care practitioner or a hospital had a problem with advocates, would that be the place to complain. We think if you have a powerful body that is identified with one group, somewhere there needs to be a body that is independent. Perhaps we need a college that can look after them, that has public input, where people can take their complaints and lodge them. You cannot leave it with the group that is their champion.

**Mr J. Wilson:** I appreciate your comments, and that is a suggestion the government should take very seriously. You mention that doctors are not lawyers and that really it may be very difficult for them. I can understand why, because the act is confusing and there is a lengthy list, for instance in section 16 of Bill 109, which requires the physician to obtain consent. There is a ranking order of people one must obtain consent from on behalf of an incapable person. Do you have any suggestions how we can improve that section?

**Ms LeBlanc:** Actually the whole idea of the hierarchy is a good one, generally. The problem is, there is a personal obligation put on the practitioner to search for all persons in any given category. When you get down into

large families or perhaps grandchildren, down at the bottom of the categories, it is going to be very difficult. We have to look at it a little more practically as to what really happens. One of the easiest ways of handling that would be to accept the consent of the person who is readily available until a person of a higher rank is available and expresses an interest in making the decisions.

**Mr J. Wilson:** I appreciate that. Finally, I was watching the news last night and I noted a lead story about a lady at McMaster University hospital who may or may not require a bone marrow transplant. The gist of the story was, the hospital was saying: "We can't afford it. We've already done nine this year. She'll have to go somewhere else." I in no way want you to comment on the case, but it does raise the issue of costs and of scarce resources that are out there now, and you have raised it here today.

There has been no cost-benefit analysis by the government. Even when we sit down with the groups in private that are very much in favour of a new advocacy system and we ask them costs, I never get an answer that is anywhere near acceptable. It is always skirted: "The principle is so important. Cost is irrelevant." Do you have any idea, any guess, first of all, at what the advocacy system might cost? Second, what will be the additional cost to the health care system in terms of Bill 109 and Bill 108? Any estimates?

**Ms LeBlanc:** We have tried and I guess what we have done is very roughly thought about it. If you looked just at the advocacy requirements for hospitals, we have 223 hospitals, we have about 1,000 nursing homes and long-term care facilities, which would all probably need round-the-clock advocates, or at least a good number would. Then you start to look at the VON nurses who are in homes, physicians in their offices and homes, and then we got lost. We just could not assign costs. Then you start looking at double visits for returns. It really is quite enormous.

**Dr Boadway:** Just to service the hospitals alone required tens of millions of dollars' worth of workers, depending on how much you paid them and how much the overhead of carrying them was.

**Mr J. Wilson:** You mentioned double visits. Maybe, because my time is done, at some point you will be able to explain exactly what that is.

**Mr Malkowski:** It is interesting to note that we have heard from a variety of presenters—and this has been mentioned before—that it has been noted that when the doctors were on strike in the west, the number of deaths actually declined, which I always find an interesting statistic. We have heard from a lot of people who have come to speak who are actually psychiatric survivors, parents of disabled children, or disabled individuals themselves, who have shared their stories and their concerns.

When we talk about specific situations that are non-emergency, non-life-threatening, and I am not talking about issues of disease or chronic illness, but other situations, we found that often doctors have diagnosed disabilities in terms of fixing the disability and "normalizing" the individual. However, the disabled community does not see the situation in the same way as many medical practitioners

do, and in fact feel they are normal the way they are and do not need "fixing."

There is also a great tendency to look towards institutionalization, which the community often does not support. A lot of medical experimentation has occurred and sometimes without complete information, without balancing risk and benefit and long-term effects. Often the parents have not been completely informed or the disabled individuals themselves have not had access to complete information. There have been people talking about psychiatric misdiagnoses and incorrect medication being given, which has had very negative impacts on their lives.

So do you agree that the medical professionals are responsible for giving complete information about treatment, including benefits and risks, prior to proceeding with treatment, and that that is the right of all individuals?

**Dr Warrack:** Certainly informed consent is important. It is paramount. In this day and age, if we do not explain the risks and benefits of treatment, then we are not doing our job properly. One of the biggest problems we have occasionally is making sure that when an explanation is given that in fact it is understood completely and totally. One of the biggest concerns I have when dealing with people in my office is: "Okay, well, here's what you've got as far as I have been able to determine. Here's what I think your options are. What would you like to do?" Often, as you know, that is the problem. They will say, "Well, what do you think, doc?" which just turns it right back on me again.

**Ms LeBlanc:** The other thing is, not only are you not doing your job right, you are at risk of civil liability or a complaint to the College of Physicians and Surgeons of Ontario.

The other thing that might be important to note is that during the time a lot of this experimentation etc went on, there was a different legal standard. It used to be based on what the reasonable practitioner would do. Now we have a reasonable patient standard, what the patient should know, and that has definitely changed the whole balance.

**Dr Boadway:** If I could just add, on a completely different note, I must say that your first comments saddened me significantly because they are not well founded in fact. Repeating that kind of thing as an example of the problem we have in attitude that comes between us, rather than being constructive, and I personally hope that we just can get past that.

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**Mr Malkowski:** Just following up one last question, some situations have been brought forward where there have been requests made, for example, to doctors for written information regarding specific medication. This was in a psychiatric situation where the doctor did not provide that. Patients have needed sign language interpreters and doctors have not given them that access, so the individual could not completely understand the ramifications. Do you not need a system or a means of dealing with complaints and issues that relates to these patient concerns?

**Dr Boadway:** Yes.

**The Chair:** Dr Warrack, Dr Boadway and Ms LeBlanc, on behalf of this committee I would like to thank you for taking the time out today and giving us your presentation.

#### CONSUMERS' ASSOCIATION OF CANADA (ONTARIO)

**The Chair:** I would like to call forward our next presenters, from the Consumers' Association of Canada (Ontario). Good morning. Just a reminder, you will be given a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes and allow questions and comments from each of the caucuses. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Ms Bushnell:** Good morning. I would like to introduce the members here. We are all coming from the Consumers' Association of Canada, the Ontario branch. To my right is Anne Louise Heron, the incoming president of the health committee. To my left is Karen Crozier, a member of the health committee as well as a lawyer, and Joanne Marshall, a member of the health committee. My name is Lucienne Bushnell and I am vice-president, issues and policy, of the association.

The Consumers' Association of Canada is an independent, non-profit, voluntary organization representing and informing consumers and advocating action on their behalf to improve the quality of life. It is the largest organized consumer group in Canada. The Ontario branch of CAC has over 40,000 members. Consumer advocacy, consumer representation and consumer education have been the major activities of CAC and of its local associations throughout its 44-year history.

Health and health care are priority issues with CAC (Ontario). One of our prime concerns is consumer access to high-quality health care at an affordable cost. The Consumers' Association of Canada policy statement on consumers and health care, which was passed in October 1989, is a detailed document explaining consumer rights and responsibilities concerning health matters, and it is attached to the document as appendix 1.

Our association firmly believes that all consumers have certain basic rights. The 1984 consumer rights of the International Organization of Consumer Unions were adopted by CAC (Ontario) in April 1991. These are the right to basic goods and services, the right to safety, the right to be protected, the right to have choices, the right to be heard, the right to redress, the right to be informed and the right to a healthy environment.

The Consumers' Association of Canada (Ontario) is fully committed to the rights of consumers to be informed and respected and to participate in reaching decisions with respect to their health care. We believe that the goal of Bill 109, the Consent to Treatment Act, is to clearly establish the right of each person in Ontario to make his or her own decision about health treatment.

Although the act thoroughly covers consent involving incapable persons, CAC (Ontario) believes that section 5 does not adequately cover everyday cases of medical treatment. In our view there are two forms of consent: written

and implied. Written consent should be required when there is a chance of significant injury, such as in surgery. Implied consent should be adequate for all other treatments.

CAC (Ontario) feels that patients are not able to make a truly informed consent with the current common practices whereby a medical resident carries a consent form to a patient the day before surgery. After providing some information in answering questions the patient may have, he or she is asked to sign the consent.

Except in emergencies, a patient should be provided with written information reinforced with oral information well in advance of the procedure. This information should describe the proposed treatment, its risks and benefits, alternative treatment and their risks and benefits, as well as the risk of doing nothing. Written information is necessary because of the inability of patients to understand and remember oral information given to them by a physician. Dr Ley, a clinical psychologist, has determined that patients experience a memory loss of up to 50% within less than five minutes of a visit to a physician.

Written information would permit patients to carefully consider the proposed treatment and discuss it with family and friends and thereby arrive at a truly informed decision regarding their treatment. A written consent form should refer to the written information that the patient has previously received, and require that the patient sign that he or she has read and understood the information. The written consent form should indicate whether any part of the procedure would be done by other than the attending physician, and require the patient to agree to it.

Regarding written information, we believe that the Ministry of Health has some responsibility. CAC (Ontario) recommends that the ministry assist the practitioners to quickly prepare the required written information. In cases where only implied consent is required, oral information should be provided describing a proposed treatment, its risks and benefits, alternative treatments and their risks and benefits, as well as the risk of no treatment. However, written information, reinforced by oral information on the patient's medication, should be provided. This will ensure that the patient understands how to take the medication and possible adverse reactions.

It should be noted that Morris and Halpern, in a 1979 American Journal of Pharmacy, concluded that written information can improve patients' knowledge and compliance with antibiotic regimens.

Dr Lowy, in his report Prescriptions for Health, recommends "printed information on prescription drugs, along with verbal reinforcement to the patient by the pharmacist." The report of the Electro-convulsive Therapy Review Committee in 1985 recommended that in addition to discussion, printed information on ECT should be provided for informed consent.

CAC (Ontario) suggests that the Ministry of Health prepare pamphlets describing what information a patient should expect from his or her practitioner regarding proposed treatments. These pamphlets should be provided to all practitioners and they should be required to display them in prominent view in their office.

CAC (Ontario) is concerned about subsections 24(1) and (2) of this act because it removes liability from the health practitioner, based on his or her belief of what is reasonable. If section 24 is implemented as proposed, no case law on consent would be able to develop, as the courts will be unable to interpret the standard of consent required. As a result, the medical lobby will accomplish in law what it failed to do in our common law courts, namely to introduce its own professional standard to take the place of what a reasonable patient in a particular patient's circumstances would want to know to be able to fully consent to treatment.

In the case of *Reibl v Hughes*, 114 Dominion Law Reports (3d), page 1, Canada's leading Supreme Court of Canada decision on consent, the court found that the professional standard is not sufficient to determine consent. Instead, the court found that a professional standard is a mere factor to be considered. The patient's objective situation must be considered in light of how a reasonable patient in that particular person's situation would have decided it. Mr Reibl consented to very risky surgery when he was close to collecting a full pension. Because his doctor reasonably decided that the patient would go ahead with the surgery, he did not disclose the risks. Mr Reibl suffered grave injury and a loss of pension. The court held that Mr Reibl had the right to determine what would happen to his body, and that the decision has to be based on what Mr Reibl felt was reasonable, not on what his doctor felt was reasonable, not the professional standard or what the doctor thought was reasonable.

#### 1130

CAC (Ontario) offers the following revised wording for subsections 24(1) and (2):

"24 (1) A health practitioner who administers treatment to a person with a consent sufficient for the purpose of this act is not liable for administering the treatment without consent.

"24 (2) A health practitioner who refrains from administering treatment to a person because of a refusal sufficient for the purposes of this act is not liable for failure to administer the treatment."

The Consumers' Association of Canada (Ontario) appreciates this opportunity to express its view on this important legislation.

**The Chair:** Thank you. Each caucus will have six minutes for questions and comments. Mr Mancini.

**Mr Mancini:** Thank you for your brief. I think your general principles and goals have been stated quite clearly in your presentation to the committee this morning and I have no difficulty in accepting those as standards we should achieve.

I wanted to ask if you were in the committee room when the Ontario Medical Association made their presentation, where they very clearly pointed out some of the practical difficulties in working with the legislation before us. I was wondering if you had an opinion on that.

**Ms Bushnell:** We were not here for the whole presentation.

**Ms Crozier:** I could offer a slight comment. I believe the medical profession has reasonable concerns about the kind of liability they will face. However, the standard the medical profession faces today in Ontario, as we know from the Prichard report, is not one that finds many practitioners liable for any damage they do.

**Mr Mancini:** I am not worried about their liability; I am worried about getting health care when I need it.

**Ms Crozier:** Right.

**Mr Mancini:** So I could not care less about someone's liability if a person's life is in danger. Appropriate delivery of service is in danger. I was not concerned about their liability. They can afford the best lawyers in Canada to defend themselves and some of them may even be former members of the Legislature. Not being a lawyer myself I do not, but I was wondering if you had had any discussion with groups like the OMA as to their practical concerns.

**Ms Crozier:** No, we have not had discussions. If I could just say briefly, though, the concerns of the medical profession are legitimate but they should be forced to work within the legislation. As you have just pointed out, they have access to the best legal minds in Canada.

**Mr Mancini:** Sure they do.

**Ms Crozier:** It is really up to the court with regard to all other professions and all other persons to set a standard which is deemed to be non-negligent or negligent. If doctors are allowed to insert their own standard into the act, it will just be something like the Health Disciplines Board, where the board can only consider whether or not the college was reasonable. The board can never make a determination of any fact in any case. People routinely go to that board, the board finds nothing wrong with the college's determination of the facts, the college finds no fault, and then the people settle out of court for a reasonably large settlement. You have to realize that you want your act to function as protection to the public, but I do not think it is harming the medical profession to say, "It is your duty as a doctor to find out what the law is, what the standard of consent is and your duty to be able to implement it."

**Mr Mancini:** Do you think it is paramount for the legislation to function practically every day?

**Ms Crozier:** Yes, absolutely.

**Mr Mancini:** Do you think it is paramount for the legislation not to jeopardize the health care of individuals who in fact need it?

**Ms Crozier:** Absolutely.

**Mr Mancini:** Given that we agree appropriate advocacy is necessary, would you not think it would be important to make sure that the theory, which is written in legislation, is able to fit hand in glove with the practicality of everyday life?

**Ms Crozier:** The proposal you are making does not fit hand in glove with the law in Canada—with the most recent treatise on the law of consent to medical treatment in Canada. It really does not fit hand in glove with the situation we have here in Ontario. As you may know, in New York state the medical standard is inserted into law, but there are

many other things in law in New York state that we do not have here.

**Mr Mancini:** What I am hearing is that the basic principles put forward in the legislation—not just from the OMA this morning but from a lot of other people who have appeared before the committee—yes, we must strive to achieve the goals to the best of our ability, and because we are only legislators, we cannot expect to be perfect. But at the same time we would want to do it in such a way that it does not infringe on the ability to be treated appropriately, quickly, when necessary and everything else in between. Frankly, I have no particular difficulty in accepting what it is we want to achieve. I just want to make sure that in the process we do not cause others, through no fault of their own, not to get the health care they truly need at the time, and that is why I am very concerned when I hear groups like the OMA and others that have appeared before the committee—I only bring them up because they were on the schedule before yourself and I thought maybe you might have heard some of their comments and it would have been good for the discussion this morning.

I only bring that up to say that when we are going to proceed with such major overhauls, sometimes in our haste we may overlook some important practicalities. But I have no trouble with the principles that are involved. I want to make sure that they work. Whether the legislation is passed June 1 or October 1 or November 15 in my view is not paramount. What is paramount is what happens the day after it is passed, because to go back and to change or to try to change three or four pieces of major legislation is not an easy thing to do. I have had some experience watching governments, previous and now present, grapple with existing legislation, and it is not easy at all.

**Mr Carr:** Thank you very much for your presentation. I have been meeting with doctors and nurses and orderlies and so on regarding this bill, and a lot of them are concerned. You may have followed in the paper. We are in the process of closing hospital beds, laying off nurses. The Joseph Brant Memorial Hospital is in the middle of my own riding. We heard last night the situation of the person who needs the transplant, who has to go up to the Premier now to get it, and we have waiting lists.

Looking at the principles you outlined in your statement, which I think are very good, there seems to be a choice of proceeding with some of these bills—and I am talking in terms of priority—or taking a comprehensive review of the entire health care system so it is there when we need it, because a lot of people—particularly, I have a senior advisory council—are saying that as we age, the services will not be there. As you know, health care costs have gone up under all governments for the last 10 years by 10% to 12%. There is a real fear out there that our health care system that we used to think was the best in the world will not be there when we need it. If you were the Minister of Health, would you be proceeding with these bills at this time, or would you be taking a look at all these other things to end the hospital beds closing and so on? Where do you see the priority in the health care system right today?

**Ms Crozier:** Do you want me to answer that? As a lawyer, my feeling about the health care system in Ontario is that it has always been fractured, that health care delivery has not been associated with health care regulation and that health care liability in the common-law courts has been hived off again from health care regulation. I suppose I have a difficulty in trying to determine why it is you would have to do one or other.

It seems to me that what we are proposing is a more stringent standard for consent to protect the public from unnecessary treatment from practitioners, who you have to admit have at least an economic interest in providing treatment. Many practitioners, I am sure, would never dream of providing unnecessary treatment, but it is really the person's decision, the patient's decision, to decide whether or not he wants to get it.

I think that in order for the patient to decide he has to have some protection in law so doctors will function today the way they functioned 10 years ago and the way they have functioned ever since the Reibl and Hughes decision. There is no reason to go back into the dark ages in law in Canada and take a step backward from Reibl and Hughes. Many lawyers feel that Reibl and Hughes does not adequately protect the public as it is. It is a standard that tends not to allow many patients to come forward and sue successfully because it is too rigid for them to overcome that standard, and in your legislation you are talking about going back 20 years in law and setting up a new regime.

1140

In New York state, where they have the medical practitioners' standard, they also have patients' rights laws built into law. They have a comprehensive quality assurance which is non-existent in Canada, according to a comprehensive study done by the General Accounting Office of the United States on our health care system, and I believe it is a tenable study. Also in New York state, patients have access to the courts. Unlike in Ontario, where the Ontario government is now paying for malpractice insurance for patients, in New York state they are not faced with their own government's \$11-million lobby in order to enforce their rights.

I would just like to make the point that in New York state there is a regime of patients' rights, there is access to the courts, and there is reasonable enforcement and quality assurance. I think in Canada we sometimes imagine that we have a wonderful system and a perfect system. In many ways we have a wonderful system, but it is not perfect. It is far from perfect. Often Canadians have not been eager to enforce their right to go to the courts. They are not individualistic in that respect, and they look to their government to provide protection.

So in answer to your question, I cannot say I would choose one. I would choose both. I think those dollars that are being wasted in the health care system now are needed elsewhere.

**Mr J. Wilson:** Thank you. Most of your comments I agree with 100%. I think the OMA made brief mention towards the end of its responses that it is trying to move to a patient standard and away from the physician standard.

Reibl and Hughes was, I think, a step in that process, although how imperfect it is.

During your presentation I could not help but think that maybe rather than spend all this money—because where I disagree with your comments is that we do have a shortage of money, and we are trying to move towards community-based care. We are never going to get there unless we find the money to get the community-based system up. We are clearly—I should stop saying “we,” because we are not doing it; we have not been the government for seven years. But the government is clearly closing down institutional care, and doing a great job of that, but the money does not seem to be going into community-based care.

**Mr Mancini:** You have lost sight of—

**Mr J. Wilson:** Yes, and we had the best health care system in the world for 42 years, as I recall.

As Health critic, I spend a lot of time with doctors. I ask them, “Do you learn anything about patient standards in medical school?” Simple. I was thinking maybe that is where we should start. That would be fairly inexpensive to introduce that into the curriculum, I would think.

**Ms Bushnell:** I would like to answer your comments. I think that what we are saying here, basically, is that the consumer has to be part of the decision-making process.

**Mr J. Wilson:** Agreed.

**Ms Bushnell:** They have a limited amount of control over saving dollars. If they go to the doctor because they have a problem and the doctor says, “Well, you know, you have to come in the hospital and we have to do this,” if they are informed, they will make a decision that will respond to their need. But if the doctor says, “I have to have these tests. I cannot proceed unless we investigate all these things,” in a way the consumer has a limited amount of control over the costs. So I think there are the two aspects of it. I think the cost of things has to be looked at, but also informing consumers and making them more aware.

I think more and more people are questioning the doctor. For example, they say: “Why do I have to have this test? I just had it done.” They go to the cardiologist and say: “My general practitioner just sent me. He did this test. Why do you have to repeat this?” So people are starting to question. People are becoming more aware about certain medications being cheaper: generic rather than brand names. So I think they can be part of the process.

Really, what we are addressing here is that if we are going to say to people, “You are responsible for your health; you change your lifestyle and you take ownership of your health,” they also have to be informed when they are making a decision about important matters such as surgery or forms of treatment. That is why we want them to be aware: “What would happen if I do nothing? Maybe things will not get any worse. Maybe that is my choice.” That is why we feel people have to be informed.

The reason we want written information is because usually when people go to the doctor, they are pretty stressed out. That is pretty true for most people, and there is a limited amount they can absorb. If they get some bad news, they really have a problem retaining some of this,

right? There is a certain denial here. That is what we are addressing, really.

We are saying, you do not give people something to calm them down on the morning of the operation and then come in and say, "Okay now, they were going to do this but you have to sign this," and the person has very little choice at that point. That is what we are saying. We are saying that if it is truly an informed consent, it has to be done differently, and those are not great costs, really. They can be uniform types of forms and fact sheets and this sort of thing.

**Mr J. Wilson:** Thank you.

**Ms Carter:** I was particularly interested in your reference to the Lowy report on page 4 of your brief. I understand that as many as 20% of admissions, particularly of elderly people to hospital, are due to drug side effects or to the interaction of drugs because some people take an alarmingly high number of different prescriptions that obviously have a lot of different ways of interacting. Also where people are confused, and again particularly elderly people, often if they are taken off the drugs that they are taking at that time they will revert back to being clear-minded. So the drugs are often the causes of that kind of problem.

You say that we need to help consumers to use their prescription drugs properly, and I think that is very definitely the case. We need to encourage more clearly written instructions. We need to encourage interaction with the pharmacist as well as the doctor because he is the expert on that, and we need to make it easy for people to be in compliance by having dosage made very clear and reminders where they need them and so on.

But I think we need to look at another aspect of this as well, which is the question of doctor education. After all, a lot of doctors were in medical school a long time ago and a lot of drugs are new. I believe the main avenue through which doctors learn about these drugs are detail men who come from, of course, the pharmaceutical companies and might be expected to have a somewhat biased view.

I wonder if you have any opinions on whether we need something else here, whether it may be some objective non-commercial equivalent of the detail men or more journals which maybe would not be filled with advertisements from the pharmaceutical companies and whether there are any other checks and balances on that kind of situation that you would suggest.

**Ms Bushnell:** Yes. This is something that we are very concerned about in the Consumers' Association. We have responded to the Lowy report and in fact we are going to be meeting several members of the Ontario College of Pharmacists in the next few weeks to specifically address that concern that oral information is not enough. It has to be backed up with written information.

This same issue that I was raising about making an informed decision is very true with the medication. Especially in the case of an elderly person in the scenario we are giving, this elderly person who goes to the doctor ends up waiting heaven knows how long in that office, is absolutely exhausted, then goes down and then waits for her or

his medication and cannot wait to get home. If the pharmacist tells them something, it is really likely that they will forget a lot of it. Then, as you say, some of them will take very many and sometimes if it is an over-the-counter type of drug they figure that that is not very dangerous. But obviously they have to realize that they are drugs and they should tell the pharmacist.

I think a great deal of the answer will come via pharmacists, who are really the experts and are recognized by the profession as being the people in the better position to really deal with the consumer education, the consumer information. For that, the general public will have to be educated to see it that way. He is not just the guy who counts pills. He has knowledge and he is the person they should talk to. They should say, "I am taking this and that and that medication," and be familiar with their medication, and not say, "Well, I'm taking a little green pill," and know what it is and how to report so that they can call their pharmacist and say: "I think I'm having these symptoms. Do you think there is a reaction here, an adverse reaction?" But I think the public has to be educated to look at their pharmacist as really the expert. I do not know if anyone wants to add something.

**Ms Heron:** I would just add one thing, and again it is in support of what Lucienne is saying in terms of the important role the pharmacist has interacting with the consumer, and that is that often consumers are also taking drugs that are non-prescription drugs. That can have implications for how prescription drugs will act.

Another point I would like to mention is that consumers need a certain amount of information before they can ask appropriate questions. If somebody gives you a diagnosis or a condition in technical terms, you are still stumbling over the syllables they have used because you cannot even figure out where the word breaks are, and you are expected to come back with questions with regard to that condition that you cannot even pronounce.

That is an awful lot to expect of a consumer, and I think that is where this whole business comes in of slowing things down and providing information that they can sit back and look at at a quieter time. If somebody tells you that you have got a condition—I bet if somebody took your blood pressure, it would spike a bit; then turns around and tells you you have high blood pressure—it is the condition and it is the stress of that situation that makes it very difficult for people to understand and respond in quite a foreign environment.

**Ms Marshall:** Perhaps I could just mention that one project the Consumers' Association is currently involved in is trying to address this problem of consumer access to health information. Recently we have set up a consumer health information service at the Metropolitan Toronto Reference Library, and it is a joint project of the Consumers' Association, of the University of Toronto, both the faculty of library and information science and the centre for health promotion, and the Toronto Hospital. So we have advice from health professionals in setting this up, but very much it has been a consumer-driven project from the beginning.

The goal of this is really to try to centralize access to health information, to bring together a really good collection of materials that have been prepared for consumers, because in the past most health information was really prepared for doctors and nurses and pharmacists, professionals. But because of the consumer movement in the health area there is starting to be a lot more material available; the problem is to bring it together and to make it accessible to consumers. I should mention that the project is funded by the government of Ontario. It has been funded under the health strategies fund of the Premier's Council on Health, Wellbeing and Social Justice.

So we really feel that access to health information is very fragmented for consumers in the province at the present time, and we are very hopeful that this service, which also has a provincial mandate, will help. We feel the public libraries across Ontario have tremendous potential to act as a source of health information. We have had many calls already from health professionals for advice on what kinds of consumer health information materials they could provide for their patients. I think there is a lot to be done, and

I am very pleased that the government has seen fit to fund this particular project.

**Ms Crozier:** I would like to make a brief comment as well.

**The Chair:** Very briefly.

**Ms Crozier:** The Canadian Compendium of Pharmaceuticals in Canada is a very economically priced manual which is available. Most doctors already have one. It provides an unbiased description of the pros and cons of uses of all drugs. I am sure every hospital ward in every hospital has one.

**Ms Carter:** Is it regularly brought up to date?

**Ms Crozier:** It is annual, sure.

**The Chair:** Ms Bushnell, Ms Heron, Ms Crozier and Ms Marshall, on behalf of the committee I would like to thank you all for coming out and giving us your presentation today. This committee stands recessed until 1:30 this afternoon.

The committee recessed at 1153.

## AFTERNOON SITTING

The committee resumed at 1353.

## PARKDALE COMMUNITY HEALTH CENTRE

**The Chair:** I call this committee back to order. I call forward our first presenter, from the Parkdale Community Health Centre. While our presenters are coming forward, I would like to remind the committee members that we do start at 1:30, and 9:30 in the morning, just so that they could get back here a little sooner in fairness to our presenters, who have been waiting.

Good afternoon. Just a reminder that you will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes, to allow for questions and comments from each of the caucuses. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Ms Diamond:** My name is Frumie Diamond. I am the community health educator at Parkdale Community Health Centre. My brief is very brief, so I will not take all the time and help you guys get back on schedule here.

I am presenting this brief on Bill 109, An Act respecting Consent to Treatment, on behalf of Parkdale Community Health Centre. We want to voice our concern about the inclusion of section 8 in Bill 109, which will limit access to confidential health care by young people under the age of 16. Subsection 8(2) clearly states that "A person who is less than 16 years of age is presumed to be incapable with respect to the treatment, but the presumption may be rebutted." This section, if implemented, will have serious consequences for the wellbeing of teens under the age of 16.

It is likely that physicians in practice will not want to face the burden of rebutting the assumption of incapability of those teens under sixteen. Putting the onus of rebuttal on the physician leaves the physician open to parental and possible court challenge. The result will be that physicians will simply refuse to provide confidential care to those under 16.

One also has to wonder how turning 16 makes someone automatically capable of making responsible decisions. The maturational process varies for different individuals along a developmental continuum. As the report of the Metro Youth Task Force, Looking to the Future, states:

"The fact that today's 12- and 13-year olds are often as sophisticated as the 16-year olds of previous generations makes the problem of age-limited services even more acute.... The task force prefers to see youth as a continuum, a period of transition between dependence on parents or guardians and eventual adult responsibility."

Common law in Canada supports the above interpretation. Precedents in Canadian common law have taken the view that minors can give consent for themselves if they understand the nature and purpose of the treatment and the consent meets the criteria for informed consent set out by the Supreme Court of Canada.

Confidential care is essential for young people, including those under the age of 16. Young people need access to information and treatment provided by health professionals without parental knowledge, particularly in the areas of birth control, sexually transmitted diseases and sexuality. These are areas where many teens feel uncomfortable about approaching their parents. Many parents also feel uncomfortable talking about such issues with their children. But even more important, many parents cannot accept that their child, particularly a daughter, may be sexually active and in need of medical care in order to acquire contraception. However, the reality is that many young teens are sexually active.

The Canada Youth and Aids Study, produced for Health and Welfare Canada, found that a significant percentage of adolescents under the age of 16 had engaged in sexual intercourse: 26% of grade 9 students, and that breaks down to 31% of males and 21% of females, and 12% of males and 8% of females in grade 7 had sexual intercourse at least once.

The teen pregnancy rate in Ontario has been decreasing. This decrease has been due to several factors, including expanded sexuality education in the schools, the introduction of family planning clinics in health units and physicians providing care to teenagers without age restrictions. It is important to maintain this downward trend for teen pregnancies, as pregnant teens have a significantly increased risk of a poor perinatal outcome. As a preventive measure, teens must be able to access confidential contraceptive and abortion services. Denying access by legislating age restrictions will not stop the sexual behaviour, but drive it further underground and increase the risks of young women becoming pregnant.

Adolescents also need access to confidential care for treatment of sexually transmitted diseases. The increase in rates for chlamydial and gonorrhoeal infection among young teens is truly alarming. Canada Diseases Weekly Report states that teens, especially females between the ages of 15 and 19, have the highest rate of chlamydial infection, and that these rates are rising. In 1990 Ontario reported over 400 cases of chlamydia infection in females under the age of 16. While trends in gonorrhoeal infection are generally dropping, the rates for girls 15 to 19 has not dropped significantly and remains at unacceptably high levels.

Both chlamydial and gonorrhoeal infections, when not treated, cause serious, long-term and often irreversible damage to the reproductive tract. Pelvic inflammatory disease, chronic pelvic pain, infertility and ectopic pregnancy are the results of these untreated infections in women. With restricted access to medical treatment due to age constraints, the epidemic of sexually transmitted diseases will only worsen.

Our recommendation: We recommend that section 8 be deleted from Bill 109. We support the continuation of the present common law arrangement whereby minors are

viewed as capable of giving consent for themselves if they understand the nature and purpose of the treatment.

1400

**Mr Poirier:** Thank you for coming forward with that. Rest assured, you are far from being the only person, community centre or medical authority that has had this identical concern. These statistics that you had have been touched on before but maybe were not as detailed as this. Obviously the government will have to scrap that section to make sure young people under 16 can have access and all confidentiality of medical health services. I cannot imagine that your wish cannot come true; it is too logical.

**Ms Diamond:** I hope so.

**Mr Poirier:** Of course, the government is invited to confirm my wish immediately, if it wants, by bringing the amendments forward. We can vote on it unanimously right now so that Ms Diamond can leave this presentation and know for a fact that is what you will do because you are such logical animals.

**Mr Winner:** I object to the term "animals."

**Mr Poirier:** I thought it was going to be "logical" that you objected to.

**Mr Carr:** Thank you very much for your presentation. One of the motions we put forward is identical to yours, and presumably the government will be listening.

I just want to comment on one thing. Two nights ago on Global they talked about some success with regard to some of the teen pregnancies: The percentage is down. Has that been your indication, having worked in the field over the last little while?

**Ms Diamond:** Yes, absolutely. The trend is decreasing, but sexual activity is not; in fact, sexual activity is increasing.

**Mr Carr:** Obviously what is happening is that we are doing a better job with some of the methods of contraception and so on. If this particular legislation comes in and there is no change, what will it do? I know in your presentation you talked a little bit about what it will do, but specifically for you, how do you see it rising? Any idea of exactly what will transpire?

**Ms Diamond:** I now work at Parkdale Community Health Centre, but for the last five or six years I have worked in the birth control field at the Bay Centre for Birth Control, which is one the largest centres in Ontario, I would say, or even in Canada. What we noted is that some of the doctors, even with the common law, are reluctant to give care to teenagers under the age of 16. Teenagers will specifically come to a clinic because they are afraid to go to their family physicians because their family physicians will tell their parents. Now family physicians are not supposed to do that, because it is supposed to be confidential, but I have known cases where that has happened.

The other thing that happens is that when some teens go to their parents, they are in physical danger. Also, their parents have thrown them out of the house, so you will have an increase in homeless youth. We also know that when these women get kicked out, this just contributes to

single moms being in poverty. They get on the welfare rolls.

**Mr Carr:** So even though the present system is not perfect, because some doctors are still going to the parents, they have an option through the clinics. Just so I know what you are saying then, it is that if this goes through, it will put the barrier up even further. It is not perfect now, but as you suggest, we are actually going to make it worse if this goes through unamended.

**Ms Diamond:** Absolutely. If this goes through, then it should be very clear to physicians—it is not just physicians but also the other health care givers who provide these kinds of services—that it is okay to treat these young people. Hopefully that will promote teens being able to have increased access, because that is what we really need. We were talking about the teen pregnancy rate, but in fact the STD rates are really at quite epidemic proportions, and we really need to be addressing that issue.

**Mr Carr:** Okay, thank you. Good luck.

**Mr Winner:** Unfortunately the parliamentary assistant for Health is called away at this point, but I would like to indicate that he said as recently as yesterday that his minister is actively looking at this section. A number of groups have come forward, including the district health officers, to share your concerns, particularly with regard to education and treatment of young women, and I do not think your concerns will go unheeded.

**Ms Diamond:** Great.

**The Chair:** Ms Diamond, on behalf on this committee, I would like to thank you for such a concise brief that got us partly back on schedule, and on behalf of the committee, I would like to thank you for coming today and giving us your presentation.

**Ms Diamond:** Great. Thank you very much, and I hope I just added another impetus to change that specific subsection.

**Mr Poirier:** You took it over the top.

**Ms Diamond:** Great.

#### ONTARIO ASSOCIATION OF NON-PROFIT HOMES AND SERVICES FOR SENIORS

**The Chair:** I would like to call forward our next presenter, the Ontario Association of Non-Profit Homes and Services for Seniors. Good afternoon. Just a reminder, you will be given a half-hour for your presentation. If you could keep your remarks to about 15 minutes, the committee would appreciate it so they would have time for questions and comments. As soon as you are comfortable, please identify yourself for the record and then proceed.

**Mr O'Kafka:** My name is Paul O'Kafka, and I am the president of OANHSS, which is the Ontario Association of Non-Profit Homes and Services for Seniors. I am also executive director of St Joseph's Villa in Dundas, Ontario. With me today is Michael Klejman, who is our executive director at OANHSS. Our comments as well will be fairly brief, and hopefully we will get you right back on schedule before we are done.

The Ontario Association of Non-Profit Homes and Services for Seniors is a non-profit, charitable corporation, and we have been in existence since 1919. Our mission and goal is to support and advance the interests of our members, thereby enhancing their ability to meet the needs of individuals and communities they serve.

The association represents over 200 organizations, providing services to in excess of 140,000 seniors, or over 10% of Ontario's elderly population. We provide these services through homes for the aged, non-profit nursing homes, seniors' housing and support services agencies. OANHSS offers our members educational and information services. In addition, group services such as purchasing, insurance, employee benefits and consulting are provided. Members of the association operate nearly 30,000 long-term care beds, over 10,000 seniors' apartment units and offer a wide variety of day and outreach programs such as respite care, Meals on Wheels, seniors' day centres, transportation, emergency response services and many others.

Membership of the association is comprised of municipal and charitable corporations which operate a variety of programs and services for seniors. Origins of our member non-profit homes go back to mid-1830s and reveal a proud history of innovative and responsive programs which are reflective of the needs of the diverse communities in Ontario.

While your committee is looking at six pieces of legislation, our comments and recommendations will be focused on three of those pieces: Bill 74 on advocacy, Bill 109, consent to treatment, and Bill 108, substitute decisions.

Starting with Bill 74 on advocacy, this bill would establish a universal advocacy system with extensive powers of intrusion. It appears to be based on the premise that currently there is little or no protection for the rights of vulnerable persons and that no one, be it family, care givers or professionals, is unbiased enough to be entrusted with decisions affecting vulnerable persons.

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There are several factors we feel need to be considered before an advocacy model is adopted:

1. Vulnerable persons are not a homogenous group. They present an incredible array of health, age, culture and environmentally related differences which today challenge our health, social service and legal systems to the utmost.

2. In the case of elderly persons, in many instances there are families and relatives who are strongly committed to their support and care. The primary obstacles these individuals face are lack of finances and a lack of understanding of how the legal and health care systems work.

3. Effective advocacy will require an extensive knowledge base of the various causes of vulnerability. There are different medical and social causes that, when coupled with unstable and difficult-to-ascertain ability to make decisions and comprehend the issues, require ongoing contact and extensive knowledge to make accurate assessments.

4. It is very unlikely that advocates can ever achieve the same degree of understanding of vulnerable individuals as family care givers or professionals who are in constant contact with these persons.

5. The proposed advocacy model is a complicated and potentially costly system. Based on the experience from

other initiatives and considering the current economic climate, we may find ourselves in a predicament of an inadequately funded program that by its very nature complicates and interferes with care and support activities in various settings.

6. This bill appears to allow and encourage the intrusion of an outside advocate, quite likely against the wishes of the next of kin, and probably without a clear understanding by the individual concerned.

After considering these points, we would like to put forward the following recommendations related to Bill 74:

1. The advocacy legislation be amended to introduce the advocacy program in two stages. In the first stage, an enlarged commission with a broader representation, to include care givers and professionals, be created to consider the following points: enhancement of existing advocacy programs; evolution of current volunteer and governance structures in care giving organizations to incorporate the advocacy functions into those organizations; an opportunity to determine the costs of possible advocacy models; the introduction of pilot projects in several communities to test out several approaches to advocacy; incorporation of safeguards into any advocacy system so that the vulnerable person's needs are served, rather than the system simply justifying its own existence and becoming the goal; and, lastly, that we incorporate into Bill 74, and amend any relevant existing legislation, to establish a requirement to report any observed or suspected abuse of vulnerable adults. This obligation should apply to all professions and to those in positions of authority over programs and agencies that deal with vulnerable persons.

2. Only when these tasks are concluded and a comprehensive report completed should the Legislature consider the establishment of an advocacy system which is cost-effective, non-bureaucratic and responsive to the needs of vulnerable persons.

I now would like to ask Mr Klejman to comment on the other two pieces of legislation.

**Mr Klejman:** Bill 109 clearly sets out the process and authority for securing consent for treatment or care to incompetent persons. It also establishes the mechanism for giving informed consent on an incapable person's behalf. The role of the next of kin, the professional, and the public guardian and trustee are established or defined. In addition, this bill imposes the advocacy functions on the process of securing consent.

For some of the same reasons stated previously in our section dealing with Bill 74, we are concerned with the impact the advocate's intervention and the Consent and Capacity Review Board's rendering of decisions will have on persons requiring care or treatment. The potential for delays, mistakes and miscommunication is amplified with each additional layer or step in the process of rendering a decision. We therefore recommend that:

1. Bill 109 be amended to delete the function of the advocate from the process of securing informed consent to treatment.

2. Provisions be made to enable a person seeking treatment or a person who has the power of attorney under the

proposed bill to obtain a review of the professional opinion via a review board.

3. Subsection 32(1) of Bill 109, referring to the review board, should be amended to empower it to act more expeditiously in giving second opinions on proposed treatments if requested by either a person seeking treatment or a person representing an incapacitated person.

Looking at Bill 108, the Substitute Decisions Act, a comprehensive and more flexible system for the assignment of the power of attorney, determination of preferred types of medical treatment in advance and the functioning of the public guardian and trustee are being proposed under this bill.

We endorse this legislation with one reservation. The provision for involvement of and authority by advocates would have the same impact on efforts to authorize substitute decisions on behalf of persons as were outlined in our comments regarding consent to treatment. The involvement by advocates will add another procedural layer, thus delaying, complicating and confusing both persons seeking decisions and others affected. We therefore recommend that:

1. Bill 108 be enacted with the deletion of references to advocates and their role.

2. An amendment be added that any person who is involved in the process of application for guardianship must report any suspected or observed cases of abuse.

In brief, concluding remarks we urge the Legislature to move ahead with this far-reaching legislation to define the substitute decision-making process and the process of obtaining consent to treatment. We also ask you to consider the importance of reaching an equilibrium between protecting individual rights and freedoms and the protection of the similar rights of others. It is at times easy to swing the pendulum of justice too far the other way in an attempt to right past mistakes.

We concur with the need to address societal issues related to disempowerment which may affect, among others, vulnerable, disabled or elderly persons. The difficulty is in trying to use these three bills to influence attitudes, change perceptions and redress economically motivated wrongs occurring in our society. We believe that it is a wrong approach and urge the committee to review all three bills with a view to simplifying the procedures and steps involved in giving consent, appointment of a third party or ensuring that rights and wellbeing are not infringed upon. We also urge the committee to acknowledge that not everything and everyone in our society is mean-spirited and that there are individuals, families, care givers and agencies which truly care and can be relied upon to seek the best for those who depend upon them. Thank you.

**Mrs Sullivan:** I am very interested in your recommendations with respect to the implementation of the Advocacy Commission, but I am particularly interested in the recommendation suggesting that there should be additional requirements on people who suspect abuse, whether it is of the frail elderly or other vulnerable people. I wonder if you would expand on that. We have heard a lot of testimony before this committee indicating that employees of institutions or agencies may be unwilling to report abuse as they

see it because of fear of reprisal from their employer. I wonder if you would expand on that and discuss the nature of the kinds of additional reporting requirements you would see as valuable.

**Mr Klejman:** I think the principle or the concept is based on the similar approach taken in looking at child protection. It certainly, in our view, makes sense to provide employees with that kind of legal requirement to free them of any perceived or real fears they may have in their own settings, wherever they may be working, whether they are facilities or community settings.

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**Mrs Sullivan:** As a matter of fact, I was just flipping through the Child and Family Services Act to find out precisely what the wording was to see if that was the kind of approach you were thinking of in your circumstances. In that act the child protection workers have a very different right of entry, through warrant. Would you think that would also be an appropriate parallel change?

**Mr Klejman:** It may be. To be honest with you, we have not developed an amendment that addresses all the issues to put forward how such legislation would make it possible for the reporting process to occur. In discussion considering this point, we thought there were some structures in the community now that could assume that responsibility.

There are agencies like adult protective service worker functions, for example, that sometimes assume that role without having the legal authority to do so. In services for the elderly, certainly it is quite conceivable that within the governing structure of boards the responsibility could be vested in the voluntary component of administration rather than looking at it in the administrative structures of agencies.

We also know that the relationship between funded organizations, transfer payment agencies and government ministries is one where there is a fairly strong reporting relationship and accountability in adherence to requirements, whether they be vested in legislation or policies. One of our views would be that there could be the kind of mechanism established within ministries that may hold the responsibility.

**Mr Carr:** I am interested in (d) on page 5 of your brief, the introduction of pilot projects in several communities to test out some of the approaches. How would you see that working? Specifically, how would you like to see it set up?

**Mr Klejman:** I think especially with the wealth of information that probably has been presented to this committee—and time permitting, we probably would have liked to sit through at least some of the presentation—a lot of ideas have probably surfaced in terms of what is happening in different sectors, in health and social services, for example, experiences that some organizations may have gone through trying to deal with problems strictly on their own. I think sometimes what we experience is that our innovative ideas do not get enough support and encouragement, in terms of government funding structures or rigid program mechanisms, to be tested in a more extensive way.

We would recommend, for example, looking at the adult protective service worker model and how it would work in the elderly services—to my knowledge, it does not exist right now; I may be wrong, but I am not aware of that system applying in a more comprehensive way to services for the elderly—taking even some of those examples and trying them in different sectors; looking at the child protection function and maybe looking at some agencies that could assume that function today, but doing it on a local basis and monitoring it a little more extensively over a period of a year or two to get a sense of whether the concept of an independent advocate is the only way to ensure that there is a strong sense of advocacy role being fulfilled in a community.

**Mr Carr:** Is that what you mean by the enhancement of the existing advocacy programs? Is it along the lines of funding that your concern is?

**Mr Klejman:** Yes. I think that when we look at some of the programs our members are providing, the areas that are often the first to fall under the axe and the last to get any kind of support in terms of ongoing funding are programs that aim to establish more of an interpersonal relationship with clients in facilities or with others who are using those facilities on a day basis.

It may be easier to obtain funding for direct nursing staff and dietary staff. When we talk about social workers or other staff with a social work focus, in current funding these are the areas that are almost the last to be considered and rarely funded.

**Mr Carr:** Looking at (c), I guess the challenge for government is to get the best possible use of some of the dollars. We all know some of the constraints the health care system is under. It is in the paper almost daily. By doing that in point (c) that you put there, “to determine costs of possible advocacy models,” I take it what you are saying is that if we do not do it properly and do not look at some of these other existing programs and the funding, we may very well spend more money than we possibly could. That is basically what you are saying.

**Mr Klejman:** The greatest fear is that a comprehensive system as proposed is introduced and not adequately funded. What we have then are obstacles in a number of areas. But due to limitations right now, that system, the advocacy system, is not able to fulfil its role, either in terms of the delays, time that people have to wait or the legal system may have to wait, or care providers or professionals in health care have to wait, simply because there is not the capacity. We have no idea what we are getting into, to be honest.

**Mr Carr:** A last question, on point (e), talking about some of the safeguards. The Ontario Medical Association was saying this morning that the health reg bills put in some checks and balances. The same principle is not here. Is there anything specific you could see, any of the safeguards you felt could be put in?

**Mr Klejman:** It is difficult to look at trying to apply ideas or suggestions to a new structure, because it is not very clear how the advocates would be established. What would be the premise for creating the agencies? Would

they be covering county structures or would they be focused on certain population numbers?

Conceivably the kind of accountability that exists in the non-profit sector, where there is in effect a local board, whether it is an elected board in a municipal home or a board of volunteers established to monitor the operation of a charitable organization—that to me, I think, would be one of the most direct accountability structures, to have a volunteer board, not appointed by a party that may be seen as subjective, to oversee the operation of advocates, whether they are volunteers or employees of the agency or organization.

**Ms Carter:** I think you are showing the same kind of difference of emphasis, if you like, that we have seen in a lot of groups that come from the care giver or the medical side. Obviously, we know that care givers, family people and professionals do provide care to vast numbers of vulnerable adults and do so very well and very effectively, but things do go wrong and I think we have a much greater sense of urgency, if you like, about that.

For example, I saw some figures this morning showing that where people are abused, it is almost always by the very people who are close to them. So we do really have a problem. Just to underline that, while we agree with the factors to be considered that you have on page 7, we really do not agree with your conclusions.

I want to read a quote from the coroner's jury at the inquest on Joseph Kendall in November 1990. They said:

“We, the jury, after sitting through 60 days of testimony, and going through tremendous amounts of evidence, are shocked and appalled at the way the vulnerable adult is being forced to live in this province. These people are Canadian citizens, and some are veterans who have fought for this country. These citizens have had their rights and dignity stripped from them, and in some cases, put into society to live in conditions that are degrading at best. These conditions put them into the position to receive all types of physical and mental abuse.

“There are a number of reports already, such as the Graham report, the Manson report, the O'Sullivan report, as well as numerous recommendations from other inquests. It is with this in mind, that we, the jury, strongly implore you to implement the following recommendations that could help to alleviate this problem.”

I put it to you that there is a problem and that we have to have the interests of the vulnerable individual at the centre of the picture when we think how best to alleviate it.

**Mr O'Krafka:** I guess our only challenge would be to look at the strengths in the existing system as well, because I am sure there are many examples of the types of things you are citing there. But there are also hundreds of thousands of examples in our member facilities, particularly in the non-profit sector which we represent, where because of volunteer governance, volunteer boards and committed staff, people are getting excellent care and services and being well advocated on their behalf.

Our key point is that some recognition needs to be given to those strengths in the system and building on those strengths, while at the same time putting protection

in for what may be a significantly lesser number of vulnerable adults.

1430

**Ms Carter:** It is understood, obviously, that in most cases there is nothing wrong, but we do need a mechanism that is aimed at the people themselves and at making sure it is their wishes and not somebody else's wishes being imposed upon them that are taken into account.

**Mr Klejman:** The dilemma we have struggled with in this report is how to translate those two concerns into a piece of legislation that does not automatically label everyone who is seen as care giver or a manager or a staff person working in a facility as someone to be distrusted or subject to suspicion that he or she is not committed to giving the best possible care or support to a vulnerable person.

**Ms Carter:** Well, we do not see it that way.

**Mr Wessenger:** I am interested in your suggestion with respect to Bill 109. As you know, the role of the advocate in Bill 109 is to provide rights advice to the patient with respect to the incapacity question and the right to challenge that. Who would you have provide that rights advice to the patient?

**Mr Klejman:** The concept we are putting forward—there is a provision in the bill to establish a review board, and the two-step process will be that, one, in the process of seeking treatment, when the professional or whoever is to provide the treatment, there is a process of exchange of information and informing what the consequences of treatment will be and what alternatives there are. I think that could be the stage at which the opportunity to appeal directly to the board rather than go through a two-step process of the advocate—

**Mr Wessenger:** So what you would recommend is that the health practitioner would give that rights advice.

**Mr Klejman:** That is right, yes.

**Mr Wessenger:** If after that rights advice the patient were to indicate that he or she wanted to object, would you see a role for an advocate visit in that instance? Obviously that person would have to be enabled in some way to object, so how would you suggest that be dealt with?

**Mr Klejman:** If the system as we conceive of it is not working, then I think at that point it would be worth considering. Again, we see the legislation as coming in tandem, so that the—

**Mr Wessenger:** Would you see perhaps the role of the advocate coming in after the rights advice by the health practitioner?

**Mr Klejman:** Not at this point, no. We would want to see that it is not working, this system.

**Mr Wessenger:** Obviously the person would have to be put in touch with either a lawyer or some person to represent his or her rights. You would agree with that?

**Mr Klejman:** That is right.

**The Chair:** Mr O'Kafka and Mr Klejman, on behalf of this committee I would like to thank you for taking the time out today and coming and giving us your presentation.

#### CAMPAIGN LIFE COALITION ONTARIO

**The Chair:** I would like to call forward our next presenters, from the Campaign Life Coalition Ontario. Good afternoon. I would just remind you that you will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, please identify yourself for the record and then proceed.

**Mrs Douglas:** Thank you and good afternoon. My name is Mary Ellen Douglas. I am the Ontario president of Campaign Life Coalition. With me today are Mrs Rhonda Wood, the Ontario coordinator for Campaign Life, Mrs Sabina McLuhan from the Toronto office, and Mrs Clare Dodds from the Toronto office. We very much appreciate the opportunity to address you this afternoon.

Campaign Life Coalition Ontario is a provincial pro-life organization working in the political arena on the life issues of euthanasia, infanticide and abortion. We are pleased to be able to present our concerns on the proposed legislation. We oppose these bills in their entirety. From our perspective, no amendments would make these bills acceptable. We base this categorical rejection of the proposed legislation on the following observations:

First, the role of the family: A major objection to the proposed legislation stems from its tendency to diminish the rights and responsibility of family members when it comes to ethical decision-making on behalf of vulnerable persons. The presumption that a person cannot trust his or her family or his or her doctor underlies Bill 108, 109 and 110. It is particularly evident in Bill 109, subsection 16(1), which defines who may consent or refuse treatment on behalf of an incapable person.

Of first authority comes a court-appointed guardian for personal care or an attorney named earlier by the now incapable person, followed by a representative appointed by the Consent and Capacity Review Board. The authority of relatives to make decisions on behalf of incapacitated family members comes after these three levels of authority. With the exception of the attorney appointed by the individual, these other categories of persons authorized to make often crucial decisions would most likely be unknown to the individual. Under Bill 109, a health care professional is directed first to seek out a stranger to make decisions, in preference to a family member. If a relative objects to such a third-party decision-making, the legislation states that the authority of the stranger is to prevail over that of the relative.

If Bill 109 should become law, it will be prudent for all individuals to ensure that they have a carefully worded advance directive to guard against the possibility that their later health care decisions will be removed from their relatives. Such advance directives, which include powers of attorney and living wills, have serious shortcomings, which will be addressed later in this brief. In addition, while it might be all very well and good for the well-informed individual to safeguard his future health decisions in this way, this is a somewhat elitist concept which will see the majority faced with battling the bureaucracy.

It is our view that the family should always be consulted first in seeking authorization to treat a vulnerable person. A relative who knows the individual should be presumed to be able to act in that person's best interests unless there is a solid reason to suspect that the life of the patient is in jeopardy. There should of course always be safeguards should familial relationships deteriorate, as they sometimes do, or when a patient is without family. However, the emphasis should be placed on the responsibility of relatives to make appropriate decisions, with legislation only as a safety net if the family integrity breaks down. In our view, Bills 108, 109 and 110 do not satisfy the secondary requirement for an appropriate safety net.

The role of government is to support the family unit, providing legislation and services to strengthen it where necessary. This proposed legislation will only serve to weaken the family structure. It sends a message to the public that families cannot protect their own; only government can.

Second, the patient-doctor relationship: The existing legal and ethical parameters of the doctor-patient relationship in Ontario have generally attempted to meet the health care needs of the public to date. While there may be some specific problems which some future legislation might address, passing these bills would compare with carrying out major surgery to repair a hangnail.

There is much public confidence in medical professionals and in the system within which they provide treatment. An underlying premise of this legislation is that doctors, unless provided with freedom from legal liability, routinely overtreat their patients, and this premise is false.

Doctors and other health care providers have as a major goal the desire to cure their patients. However, not all patients can be cured. When cure is no longer possible, the role of the medical professional is to offer medical treatment and nursing care which will alleviate the physical suffering of the patients, as well as to address the emotional and spiritual needs of the patients and their families. This second role of the medical profession is becoming better understood both within the profession and within our society as a whole.

Third, the right to refuse treatment and informed consent: Patients already have the right to refuse medical treatment. This principle of personal autonomy has a long tradition in the common law. Therefore, as the Law Reform Commission of Canada pointed out in 1979:

"The very fact that a law is deemed necessary to assure patients' rights implies, and therefore tends to reinforce, an erroneous presupposition about the locus of decision-making in the physician-patient relationship."

The bureaucratic mechanisms introduced by this proposed legislation will literally force people into trying to predict the future to ensure adequate care.

We must be realistic. How many of us can make solid, well-informed decisions about what we might need, let alone want, among many possible options, with an unknown medical condition, under unknown circumstances, at an unspecified age and location, with no documented health history leading to this particular event and no opportunity for prognosis? Are average citizens expected to have a

sound grasp of potential medical treatments available in any and every situation? How many would think to specify that they should be fed to prevent death from starvation?

The individual's right to consent or refuse medical treatment is grounded in the notion of informed consent. Such consent to medical procedures requires complete, accurate and up-to-date information on a specific medical condition, as well as a discussion of alternatives before decision-making. The bureaucratic business of these bills, with their governmental invasion into matters best handled by the individual, his or her relatives and compassionate health professionals, will make caring for vulnerable persons more difficult.

Mrs Wood will continue from here.

1440

**Mrs Wood:** Fourth, a formula for cost containment: These bills are thinly disguised mechanisms to reduce patient services and to cut health care budgets. Campaign Life Coalition Ontario strongly objects to such cost-containment measures being practised on some of the most vulnerable members of our society.

The "Big Brother knows best" ideology implicit in this legislation is further underscored by close study of Bill 108, section 46, the definition of "incapacity regarding personal care," and sections 52 to 62 concerning court-appointed guardians of the person. These sections put in place a court procedure that could be used to reduce health care or even lead to euthanasia for our most vulnerable and defenceless elderly, the poor and indigent.

Abuse of elderly patients by health care providers, hospitals and geriatric institutions may be an occasional problem under our present system, but it is the demonstrated decency and responsibility of health care professionals, together with existing legal protection for the patient, that makes any systemic practice of euthanasia unlikely. This legislation, however, which removes ethical decision-making from the family and health care professionals and places it into the hands of a court-appointed guardian, would put in place a system that would allow for euthanizing our elderly poor as a cost-containment mechanism.

While this may seem an overly Orwellian dramatization, the possibility of euthanizing the poor and vulnerable elderly is a real concern to the pro-life movement. It is a fact that the ever-increasing percentage of our population over the age of 65, a percentage to reach 28.8% by the year 2036, is placing an increasing burden to provide funds for health care and pensions on a decreasing percentage of our workers. Tax dollars, as this government well knows, are not increasing fast enough to cover the increasing social needs of Ontario's residents. We reject, however, that any saving of health care costs should be obtained through removing protection for the most vulnerable in our society.

These proposed bills would place a vast bureaucracy between doctor and patient. This bureaucracy will have an enormous power over people's lives, and yet the qualifications and duties of the assessors and advocates called for under the legislation are either poorly defined in the bills or not defined at all. It is unacceptable that civil servant

positions of such responsibility are proposed without public scrutiny of their job descriptions.

Of further concern is the cost of this veritable army of civil servants. The government has already estimated it will cost between \$20 million and \$30 million a year to administer this system. Will the health care system be put under a further strain to pay for it?

Fifth, the right to nutrition and hydration: "Treatment" is defined so broadly in Bill 109 that it could be interpreted to include nutrition and hydration. This could lead a guardian or attorney for personal care to request that food and water be withdrawn, in effect permitting the patient to die from starvation. Food and water, even when supplied through assisted feeding, is not medical treatment; it is ordinary medical care. There may come a time during the dying process when nutrition and hydration becomes burdensome for the patient because the body is no longer capable of processing food and liquids. However, while food and water is still of benefit to the patient, it should be clearly understood that its withdrawal is unethical and prohibited.

Proponents of euthanasia consider the withdrawal of food and water to be the first step towards active euthanasia. Helga Kuhse, director of the Center for Human Bioethics at Monash University in Melbourne, has stated, "If we can get people to accept the removal of all treatment and care, especially the removal of food and fluids, they will see what a painful way this is to die, and then, in the patient's best interest, they will accept the lethal injection."

Sixth, living wills: Although the proposed bills do not provide directly for living wills, the practical effect of Bill 108 is to introduce living wills to Ontario through legislation of powers of attorney for personal care. Subsection 47(5) will allow the attorney to give or refuse consent to "specified kinds of treatment under specified circumstances."

Living wills are ostensibly designed to give effect to rational, informed choices of competent adults, should they become incompetent at a later date. The underlying premise of a living will is that the doctors, unless threatened with legal action, routinely overtreat their patients. This can destroy the doctor-patient relationship and erode the trust that has been the traditional cornerstone of ethical patient care. It implies that in the absence of such a document, one can expect to be treated excessively. It implies as well that the patient has no right to refuse treatment or to refuse the advice of a physician. The living will suggests that these rights must be acquired by the issuance of a legal document.

The living will undermines the professional judgement of the physician. In dealing with an incompetent patient, physicians determine the course of treatment by taking into consideration many factors such as the apparent wishes of the patient, the wishes of the patient's family, the patient's condition, and the nature and availability of treatments. This weighing of factors should take place as an integral part of good medicine, the goal of which is to determine the best interests of the patient and then to act accordingly. Living wills compel a doctor to act in a certain manner, dictated by a written document that could not possibly encompass all scenarios.

Of great concern to Campaign Life Coalition Ontario is the origin of the living will and the long-term goals of its proponents. The original name for the Society for the Right to Die was the Euthanasia Society of America, founded in the 1930s to promote euthanasia, whether voluntary or involuntary. At a meeting of the Euthanasia Society, Luis Kutner, a Chicago attorney, introduced a new document designed to bring about a change in the "climate of society" before euthanasia would be acceptable to the public. This document was called the living will. Three years ago, at a worldwide meeting of euthanasia organizations, the living will was touted as the "first short step" to death on demand.

Derek Humphry, co-founder of the US Hemlock Society and president of the World Federation of Right to Die Societies, advocates the use of living wills to achieve euthanasia. "We have to go stage by stage with the living will, with the power of attorney...we have to go stage by stage."

In Canada, Dying with Dignity, founded in June 1980, has concentrated on promoting living wills and has steadily lobbied the medical profession to support this document.

#### 1450

In November 1991, Professor Eike-Henner Kluge, a medical ethicist from the University of Victoria, appeared before the federal legislative committee H to testify on Bill C-203, An Act to amend the Criminal Code re Terminally Ill Persons. He proposed that this bill be amended to allow incompetent persons to appoint proxy decision-makers. Bill C-203, since defeated, would have allowed for active euthanasia. We are deeply concerned that living wills or powers of attorney could be so worded as to permit a third party to authorize the direct medical killing of vulnerable persons.

Professor Kluge's proposed amendments to Bill C-203 were fully supported by the British Columbia-based Right to Die Society of Canada. This group, recently founded by writer John Hofsess, has publicly stated that its goal is to legalize active euthanasia in Canada.

Euthanasia organizations throughout the world have endorsed and worked for living will and power of attorney legislation for many years now. Such documents are the first step in softening up social attitudes towards killing the vulnerable, whether young or elderly. The pro-life movement in Canada is opposed to this step.

Campaign Life Coalition Ontario recommends that Bills 108, 109 and 110 be defeated. We believe these bills would be dangerous for patients if enacted as drafted and cannot be amended satisfactorily. We offer the following observations:

Physicians, along with patients, family members, health professionals and/or clergy make decisions every day to not initiate or to discontinue unnecessary and heroic measures. Patients have the right to consult with or choose another doctor if they believe they are being overtreated or undertreated. Individuals already have the right to give physicians and families their instructions in case of incompetency and/or terminal illness.

There is no law, medical group, church or anti-euthanasia organization that insists we use unnecessary, useless, heroic

or unduly burdensome measures to keep a dying person alive. A chronically ill, disabled or dying person, like any human individual, has the right to compassionate, humane and commonsense treatment and care allowing him or her to live with dignity until the moment of natural death.

**Mrs Sullivan:** Your brief is one that four minutes of questioning from each caucus really will not do justice to because, as several other presenters have done, I think you have come before the committee raising fundamental ethical and moral questions.

My sense of these bills is not that they would permit euthanasia. I understand you are saying they may well be the first step to later legislation and that you see that euthanasia could be a result of the implementation of these bills. I will certainly review the bills in relationship to the concerns you have raised, and I am sure other members will, but that is not my reading of them.

Having seen that the Ontario Medical Association is now undertaking a dialogue, which I understand will occur over the next year, in relationship to the scope of practice of physicians and their ethical and professional requirements, I wonder whether you have spoken with the Ontario Medical Association about presenting your views before it on these questions and whether indeed you have addressed it with your concerns about these bills in relationship to the euthanasia issues.

**Mrs Douglas:** I would like to ask Sabina.

**Mrs McLuhan:** No, we have not talked to the OMA. Usually we do not find our position is greeted very cheerfully by the OMA, and on this we have been working among our own network of pro-life groups. I would suggest, though, that I think you can read euthanasia into these bills simply from the point of view. If you have a court-appointed guardian of the person who believes, from an ethical viewpoint, that a disabled or vulnerable person is better off dead, then he or she as guardian could very well endorse some kind of action which would indeed end the life of that person.

**Mrs Sullivan:** You have indicated at the conclusion of your brief that "There is no law, medical group, church or anti-euthanasia organization which insists we use unnecessary, useless, heroic or unduly burdensome measures to keep a dying person alive." That, it seems to me, is more the intent and indeed the power of these bills than the actual provision of permission to kill. I find it very interesting that we are seeing on the opposition—I do not think these bills are awfully fabulous, but I just do not see them going as far as you think they are going.

**Mrs McLuhan:** Perhaps we are just very jaundiced.

**Mrs Sullivan:** I will re-read them, and I am sure everybody else will as well.

**Mr J. Wilson:** I appreciated your conclusion in particular, because I made a note in the middle of the brief that I was beginning to wonder whether the highest ideal in society was really life or justice; you know, that argument we have, having studied ethics at university. But at the end you make it clear that it is really a just life that is the highest ideal in society. We tend to forget that around here.

Just to follow on what Mrs Sullivan has said, I can see your argument for this being the beginning of the slippery slope—and I do not particularly like the legislation; I do not think that is any secret around here—but I will have to re-read it in light of your comments. It is not so much that a guardian may choose to end someone's life prematurely, because in looking at guardianship, the likelihood is the court, I would think, would try to appoint as guardian someone who is familiar with the patient and is in the best interests of the patient. That is what I would like to think anyway, but I will re-read and revisit that.

I am particularly interested in page 6—this follows along the exact same line—where you see these bills as being also a formula for cost containment. It is probably the boldest statement yet made about this legislation and it certainly shines light on the legislation. I am amazed by it because as I was reading the legislation and going through briefings several weeks ago, in fact months ago, the thought crossed my mind, and here I am faced with the first brief that actually brings it forward.

Have you talked to other groups outside your own group, which is extensive, I know? You mentioned that your relationship with the OMA may not be the best, but do other groups share this vision or this reading into the bills?

**Mrs McLuhan:** It is actually very difficult, as we have found, to talk to very many people about these bills at all because they are so complicated that it takes months of reading before you can even begin to try to understand what they are saying unless you have some kind of legal background. We find this whole issue of living will legislation and power of attorney legislation, which we definitely believe would lead to euthanasia down the road, is a very new issue in our society. People do not like to talk about dying, so people do not tend to talk about these subjects. We have found, in the last six months in particular, that we have had to have a really heavy emphasis on discussing this among ourselves and with the people we rely on for ethical advice. In turn, we hope to be able to go into the wider public and raise our concerns, so this is just the start of this issue as far as we can see.

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**Mr J. Wilson:** I appreciate that. Given that this legislation in all likelihood will pass in some form, and we think it certainly needs major amendments, but given that it might, can you see living wills—or, as you say, it really is in the bill itself: powers of attorney for personal care or guardianship—being of some benefit?

We are moving very rapidly into a system of rationing health care. That is fairly evident. Look at all the things that have been cut in the last two to three months by this government in terms of procedures that were paid for under OHIP and are no longer paid. I am a Health critic. I get letters and phone calls every day. In fact, we had the example last night of the lady who needs a bone marrow transplant at McMaster University hospital and the hospital saying: "We have done nine this year. We cannot afford to do any more. You will have to go somewhere else."

Maybe it actually will help sustain life if people are able to write ahead of time, "Yes, I do want," contrary to what the new system is, which is to ration health care. Maybe you can do the opposite in your will and write, "I want everything possible done, and I am willing to mortgage the house or whatever to ensure that you do everything possible to sustain my life for as long as possible." It is an extreme argument.

**Mrs Douglas:** I think the point made in the brief with regard to how much money it is going to cost to administer this particular legislation points out that it really is not going to be a saving to the general public. I do not think we should ever put a cost factor on life so that we are saying the pressure is on the person who has an illness to feel obliged to exit, because he or she is becoming a burden financially to society.

**Mr J. Wilson:** Yes, but society is moving that way anyway. I do not want to see it either, but it is a debate we must have. It is being forced, I think.

**Mrs Douglas:** The point that as the population moves on we are losing the base for taxation is a very frightening one too, because there are going to be very many more older people in the next generation. We have wiped out so much of our population through abortion that there is not going to be that tax base there to support the elderly, so we have to have legislation in place now that will protect the lives of individuals. We cannot begin to chip away at that value.

**Mr Wessinger:** I am having some difficulty understanding your position with respect to the legislation, because I got the impression you did agree with the concept that individuals should have power to make their own decisions with respect to medical treatment. Am I correct that you do agree with that principle?

**Mrs McLuhan:** Yes, we agree with that.

**Mr Wessinger:** Okay. If they have the right to make decisions concerning their own medical treatment, should they not be able to designate a person to make that choice on their behalf in the event that they are incapable?

**Mrs McLuhan:** We are very frightened that people would be forced into having to pick people who perhaps would not be working in their best interests. As we pointed out in the brief, the line of authority seems to stretch towards third parties first, and then goes down the line to having family members involved in these decisions.

**Mr J. Wilson:** If you look at section 16 of the act, paragraphs 1, 2, 3 and 4, first of all, there is the power of attorney.

**Mrs McLuhan:** Which bill are you looking at?

**Mr J. Wilson:** This is section 16 of the Consent to Treatment Act, and if you look at that act, you will see in paragraphs 1, 2 and 3, these are allegedly the third parties. Let's just consider who they are. There is a person named as a power of attorney, so that is a person selected by the patient, or the individual himself or herself, to make a decision on his or her behalf. The other possibility is a person's representative. That again is a person chosen by the patient to make a decision on his or her behalf. The

only third party coming ahead is a guardian appointed out of the Substitute Decisions Act, and under that act, family members would obviously have a preferential position with respect to being appointed guardian.

If you go to paragraph 4, there is a list of the family: the spouse, child, parent. So to me, the family is very much involved. They are the primary parties, unless the individual himself or herself has basically chosen another party to make that decision on his or her behalf. It would seem to me that an individual should have the autonomy to choose someone other than a family member to make a decision for him or her if he or she so wishes.

**Mrs McLuhan:** The way we read it was that the intent seemed to put the court-appointed person to start with, above the family. Certainly, if a person chooses to appoint whoever he or she wishes, that is no problem. But we were really concerned that the whole emphasis of these bills seemed to be trying to remove the family from looking after their vulnerable relatives, and we are very concerned about that kind of philosophy.

**Mr Wessinger:** That is certainly not the way the bill is drafted, in my opinion. I think Mr Winninger may have some comments, but it is an act with respect to the appointment of a guardian. It is certainly the family, as far as the act is drafted. They have the first right, unless the person decides to name someone else.

**Mr Winninger:** Just two points: You acknowledge, in your conclusion on page 13, that individuals already have the right to give physicians and families their instructions in case of incompetency and/or terminal illness. My first question would be, what is wrong with writing that down in a power of attorney for personal care so there is no doubt or ambiguity about what the intentions are?

**Mrs McLuhan:** I think the powers of attorney and the forms of living wills we have seen that have been endorsed in various states in the United States, for example, tend to leave great gaps in exactly how to interpret some of the things that are written down. You can, for example, say you would not want to have extraordinary medical treatment administered under certain conditions, and various American courts have ruled that extraordinary medical treatment includes food and nutrition. We think that is quite a barbaric way for somebody to die, ie, to be starved to death, which can take many days and be very painful. We are very concerned that the forms used by people to give their advance directives could in some cases have legal trucks blown through them by people who actually have another agenda in mind.

**Mr Winninger:** But you realize that power of attorney for personal care does not necessarily deal exclusively with withdrawal of heroic measures or life-saving treatment. It also deals with survival, life-sustaining treatment, and choices that the donor of the power of attorney makes with regard to the kind of care that will sustain that person's life if he or she becomes incapable.

**Mrs McLuhan:** Again, the American experience would lead us to presume that most of these documents in fact only refer to withdrawing treatment from people, and do not always give the right to have treatment continued. If

the document does indeed specify that treatment must be continued, that would be fine, but if it is only to cover withdrawing treatment we would be very concerned about that.

**Mr Winninger:** I think it is a little dangerous to use only the American precedent as your yardstick. Thank you.

**The Chair:** Mrs Douglas, Mrs Woods, Mrs McLuhan and Mrs Dodds, on behalf of this committee I would like to thank you for taking the time out this afternoon and giving us your presentation.

**Mrs Douglas:** We would like to thank you very much for having us.

#### ONTARIO DENTAL ASSOCIATION

**The Chair:** I would like to call forward our next presenters from the Ontario Dental Association. Good afternoon. Just a reminder that you will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each caucus. As soon as you are comfortable, please identify yourself for the record and then proceed.

**Dr Somer:** My name is David Somer and I am president of the Ontario Dental Association. With me today is our director of professional affairs, Ms Linda Samek. We are here on behalf of the ODA, which is the voluntary association which represents more than 5,000 dentists in Ontario.

The mission of the Ontario Dental Association is to support its members in the delivery of exemplary oral health services to the residents of Ontario. Our members provide dental services in partnership with their patients. This partnership is based on the goal of the Consent to Treatment Act that the Minister of Health outlined to members of this committee last December. In her words, "The goal of this legislation is clearly to establish the right of each person in Ontario to make his or her own decisions about health treatment."

We are here today to reiterate our support for the concept of self-determination through informed consent. We believe it is essential for patients to know, first, the findings of their oral health assessment, second, the related treatment options and, third, the probable outcomes, including potential benefits and risks that might be associated with each of the options. Without this information, the patient is not able to choose an appropriate treatment plan. In fact, we would argue that this communication process already serves as the foundation of the patient-practitioner relationship, a relationship that is built on trust.

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The ODA supports the patient's right to self-determination; however, we also recognize the need to ensure patient protection. Ontario dentists are aware of the vulnerability of the incapable person. It is because of our strong support for patient rights and protection that we are here to outline our serious concerns about some aspects of Bill 109, the Consent to Treatment Act, Bill 108, the Substitute Decisions Act, and Bill 74, the Advocacy Act. For the most

part, we will concentrate our comments on the Consent to Treatment Act.

In our view, legislation designed to protect vulnerable patients must not be so complex that it serves as a barrier to the provision of needed health services. Unfortunately, the legislative initiatives we see before us lack internal consistency. Because the bills are not complementary, both the practitioner and the patient are vulnerable.

The definition of "treatment" is a prime example of the confusion practitioners will face under this legislation. Under Bill 109, "'treatment' means anything that is done for a therapeutic, preventive, palliative, diagnostic, cosmetic or other health-related purpose, and includes a course of treatment."

Our concern is that this definition is so broad that a practitioner actually may be prohibited from performing a necessary examination or diagnostic procedure to determine the urgency of a patient's condition. Even if the practitioner is able to determine the need for care, there will be circumstances where we will be unable to provide relief from pain for the incapable patient until the process outlined in the bills has been completed and the substitute decision-maker has been located to provide authorization for needed care.

The legislative package before us does not balance the patient's right to consent to treatment with his or her right to receive treatment. As health care professionals, we recognize that there will always be situations that patients and their families will consider emergencies requiring care, at least to relieve pain. Consider for a moment the needs of the confused Alzheimer's patient who would be forced to suffer pain needlessly as we contacted the advocate and waited for the permission of a substitute decision-maker.

In most instances, the same family member who brought the patient to the office for care also will serve as the appropriate substitute decision-maker. Even with this knowledge, practitioners would be unable to perform basic procedures such as examining the incapable patient or providing relief from pain until the entire process has been completed.

Is it not ironic that the stated purpose of the Advocacy Act is to acknowledge, encourage and enhance individual family and community support for the security and wellbeing of vulnerable persons? Yet, when combined with the Consent to Treatment Act, we find that the consent provided by the responsible family member must be set aside until an advocate has informed the patient of his or her right to challenge the finding of incapacity.

It is true that Bill 109 attempts to recognize and provide for patient care in exceptional emergency situations where the patient would "suffer serious bodily harm within 12 hours if the treatment is not administered promptly." How will we make that determination if we are not even permitted to diagnose a patient's condition?

As we touch on the emergency provisions, we wish to expand on some of the problems that may arise because of delays in working through the appeal process. A panel of the review board must commence a hearing within seven days of the receipt of written notice of a proceeding. Even though the board is required to render its decision within

one day after the end of the hearing, under the Consent to Treatment Act, emergency care may be continued for only 72 hours. We need to ensure that this legislative package provides for the review process to be concluded in a timely manner. If the provision of emergency care is to be restricted to 72 hours, we believe it would be unreasonable to extend the hearing process to seven days.

We might add that we are not certain of the role of the practitioner in the hearing process. What information will be provided to the board members to assist them in making a decision? Will the practitioner be required to complete a detailed report about his or her finding? Will the practitioner be requested to take time from practice to appear at the hearing? Will the patient be required to appear at the hearing?

Another of our concerns relates to the development of criteria for the determination of capacity. Just a few of the many health care practitioners who will be required to comply with this legislation include chiropodists, chiropractors, massage therapists, physiotherapists, dentists, optometrists and physicians. Because all practitioners do not have training in assessing either the mental capacity or reasoning abilities of an individual, we believe that the inclusion of a set of criteria would go a long way towards ensuring that patients are treated in a consistent manner in their contacts with health care practitioners. We recognize that the legislation envisions such criteria being prescribed under the regulations. On this point, we ask that the regulation-making process include full consultation with the affected practitioners.

The age of consent is another issue Ontario dentists wish to discuss. It is the interference in both the patient-practitioner relationship and the family unit that we find most offensive. As primary care practitioners who treat a large number of children, we recognize the family unit and the role of parental responsibility in care and decision-making on behalf of minor children. This act would interfere with the traditional role of the parent in routine health care decision-making on behalf of the child.

Bill 74, the Advocacy Act, states that it only applies to those over 16 years of age, yet the Consent to Treatment Act requires practitioners to contact an advocate for those under 16 years of age if they demonstrate a wish to give or refuse consent to treatment.

We have all read the news stories about how this legislation would delay the provision of care for the child who may fuss or refuse treatment. I think it is important for us to follow this process through and consider the real impact on the patient and the health care system.

Under the Consent to Treatment Act the child who refuses treatment will be in control. Even though the practitioner and the parent already have agreed on an appropriate treatment plan in most cases, treatment will be delayed while the practitioner explains his or her findings to the child and then documents the fact in writing for the child to review. Next, the practitioner places a call for an advocate to attend and inform the child that he or she has been judged incompetent with respect to the treatment decision and has a right to appeal that decision. In turn, the advocate informs the practitioner, either orally or in writ-

ing, that the patient does or does not wish to appeal this finding to the board.

How long will it be necessary to wait for the advocate? At this time it is not clear to us exactly how we set the advocacy process in motion. Will there be a central 800 number or will each community develop and promote its own advocacy services? Can we be assured that an advocate will be available for our patients when and if they are needed?

In rural communities and in the north, the parents might have travelled many miles to have their child examined and treated. Now, the appointment time is used for the administrative details and contacting the advocate and waiting. Appointments will be rescheduled and care might be delayed. For the child and the parent, this means more time away from school and work. In some areas travel costs are extraordinary, and where northern travel grants provide for related travel costs, an avoidable cost burden is placed on the health care system.

Of course, dentists are concerned about the unnecessary complexities of setting the advocacy process in motion for the uncooperative child. However, this legislation also recognizes that consent to treatment may be express or implied. Therefore, we have specific concerns about the implied consent a child gives. Would this necessitate the involvement of an advocate in virtually every treatment provided to those under 16? Will we be required to have advocates assigned to every dental office where treatment is provided to children? If this is the case, will there be enough advocates to go around? Will there be enough funds to support this new system?

As health care providers, we see a complex layer of bureaucracy that may create needless delays in day-to-day management issues regarding patients. We see treatment delays that will have a negative impact on the quality of health care provided to our patients.

According to the Minister of Health, this is not the intent of the legislation. The minister reported to this committee that "...malicious obedience can present us with all sorts of problems." We are here to tell you that poorly worded legislation will cause problems and will add unnecessary costs to the delivery of care.

Practitioners are required to comply with the law. We must not blame the practitioner when the outcome of his or her compliance differs from the intent of the law. This legislation outlines a process, and if that process is not to be followed, we recommend that amendments be brought forward to fix the problems that many of us have identified. In the interim, as responsible professional organizations, we must inform our members of their responsibilities under the legislation.

Let me say that our concerns are not limited to the child. As I pointed out earlier, our views about this legislation are similar when we consider the elderly patient who relies on his child or some other family member for some aspects of his decision-making. The family unit is an integral component within our society. The Consent to Treatment Act recognizes the important role of the family in naming the spouse, partner, child, parent, brother, sister or other relative as those who may refuse or consent to treatment

on behalf of the incapable person. Yet they are not able to act on behalf of the patient unless an advocate has carried out his or her role under the act or a guardian has been granted authority under the Substitute Decisions Act or through a power of attorney.

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As a dentist in private practice, Bill 109 frightens me. I believe that there will be a variety of circumstances where the current bills will prohibit my colleagues and me from providing good dental care on a timely basis. The process is so complex that it is virtually unworkable. The paediatric specialists and those who work with the elderly will spend much of their time writing letters to patients, contacting advocates and determining the appropriate substitute decision-maker. In some offices there will be very little time for patient care. Also, in some instances our practices will become engulfed in administrative details related to Bill 109, the Consent to Treatment Act. As a result, the outcome will create a negative impact on the wellbeing on our patients.

There are many questions about this legislative package. As health care practitioners under the Health Disciplines Act we are held accountable for the care that we provide. We are specially educated, clinically trained and licensed to provide services within a specified scope of practice. There is a public complaints process where questions about the service that we provide may be raised. We believe that advocates who will have access to patient records also need to have clearly defined lines of accountability. This step is essential to ensure adequate patient protection and privacy.

The members of our association have attempted to address the very real barriers to care that many of our patients will face as a result of this legislative package. Despite all of our efforts, we were unable to come up with a simple, direct solution to the problems we see. We cannot underestimate the challenge we have before us. In their current formats, the bills are quite simply unworkable.

As health care professionals we support the principles and intent of the three bills. Unfortunately the outcome of this legislation will leave the very patients we all want to protect more vulnerable than ever before. Therefore we ask that the bills be reviewed with the intent of redrafting. Further, we ask for a full consultation process prior to the reintroduction of the revised legislative package. This consultation should involve health care providers and consumer representatives.

We reiterate our support for individual autonomy. We agree that autonomy incorporates the principle of informed consent. As health care practitioners, we look forward to exploring how we might achieve the intended goals of the legislation without compromising the delivery of health care and escalating administrative costs. When the Minister of Health herself said that "adherence to these laws is considered to be malicious behaviour," obviously there is something deeply flawed in the proposed legislation. The ODA offers our assistance to the members of this committee. Thank you very much.

**The Chair:** Thank you. Each caucus will have about four minutes for questions and comments.

**Mrs Sullivan:** This is a very useful presentation for the committee, and one that in many ways is reflected by presentations that have been made by other health care practitioners. Your discussion relating to the definition of treatment, your discussion about training and determining capacity for your own profession and for, I put it to you, allied professions in dentistry, your discussion of the harm to the patient that may result from the delay because of the advocacy, the bureaucratic tangle, the lack of accountability for advocates, the access to clinical records and indeed the question of why an advocate would need or require access to dental records for purposes of advocacy is one that stands in my mind.

I am most impressed, of course, with your second-last paragraph, which asks that these bills be withdrawn, redrafted, and that a full consultation program occur with health care providers and consumers. Those are things that we have been demanding for our party. While the intent is laudable, we do not feel that they are workable.

Yesterday we had an indication that there will not be a full consultation process prior to the final consideration on a clause-by-clause basis of these bills. Frankly, we just think that is a nonsensical approach, given the complexity of the legislation and the difficulties and conflicts it would put into place. As a result of that situation, I am basically passing on information to you rather than asking you questions, because we agree with what you are saying.

**Mr Poirier:** Very briefly, how much consultation did you have before this was brought forward?

**Dr Somer:** Virtually none. There was some consultation way back in I think it was 1988 in response to—

**Ms Samek:** In 1989 and 1990 there were principles proposed on consent, but that was in a previous time frame, and nothing had come forward since then. Clearly we never saw anything on advocacy, and we think that consultation was very, very limited.

**Mr Carr:** Thank you very much for your presentation. I am looking at it from the perspective of, say, an average dentist; take my dentist in Oakville. What is it going to mean to the actual operations of a dental office if this legislation goes through?

**Dr Somer:** It is not so much the delays in treatment as far as the practitioner is concerned, but it may have very profound effects on patients who have treatment delayed because of this act. I think that is where our concern comes from; particularly, as I mentioned, a patient who may be in pain and is really not capable of giving consent, although the parent might be right there within the examining room who is quite capable of giving consent and providing advice and help in treatment and management of that particular patient. To my mind it takes away that parental right and hands it over to a bureaucracy that is probably not needed. That is where I think the problems come in, in delay of treatment.

**Mr Carr:** Also as it relates to that, what is your feeling in terms of the associated costs that are going to be involved, costs escalating, whether they be in the medical

field or dental, dramatically? How do you see this affecting the cost of the delivery of the services?

**Dr Somer:** Any time you set up a new bureaucracy to deal with a situation like this there are going to be associated costs with it. How high those costs are going to be is not for me to determine. I think that most of the cost will come out of the pocket of the average taxpayer, not necessarily out of my patient or dentists' or doctors' patients, although perhaps in some cases that may be the case, but more so generally in regard to the costs to the taxpayer.

**Mr Carr:** Of course, as you mentioned, a lot of dentists who went through school thinking they were going to spend a lot of time actually working on people should have taken a lot of courses in paperwork and administration because that seems to be a lot of what they will be involved in.

Just as it relates to consultation as well—I know it was touched on earlier—because I think it is very important, I am getting a tremendous amount of feedback from the dentists in my area. As a matter of fact I have them on my desk, and I read them every day as they start coming in. So they are now, as a result of this, coming in. I just wanted to make it clear that up to this point, your involvement has been very little in terms of the government and consultation, even though this probably will affect you more than anything that has come down the pike in a long time.

**Dr Somer:** Other than the Regulated Health Professions Act, yes, that is quite correct. We would certainly be willing to act in a consultative role and to talk to this committee or the ministry or whomever in regard to the way this act can be improved to make sure that care is not denied to anybody.

**Mr Carr:** Just in terms of letting your members know, one of the big concerns is that a lot of people are under so many pressures in the day-to-day they sometimes do not know until pieces of legislation are brought in. What type of feedback are you getting from your members now over this?

**Dr Somer:** "Irate" would maybe be not too strong a word. Confusion and concern perhaps are the response.

**Mr Carr:** They cannot believe the government would actually do this, is what I am getting.

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**Dr Somer:** Well, they are hoping, but there certainly is a lot of confusion as to how it will affect the relationship with the patients and with the families they have in their own particular practices. That is my concern and it is certainly the concern of most other dentists I have talked to about this.

**Mr Wessenger:** Thank you for your presentation. I have a question to you. With the situation in respect to incapable adults there is no process or legal procedure for you to treat an incapable adult right now under the existing law, unless there is a committee for the person appointed. So I am just wondering, in fact, how you treat incapable people now, so as to give us some guidance of how we should frame our legislation. Since you do not have any

legal right to treat them now, I am wondering how you in fact treat an incapable adult.

**Dr Somer:** In almost all cases it is as a result of consultation with a relative of an incapable person who will give consent to treatment.

**Mr Wessenger:** Right. So you will look to the closest relative to give instructions.

**Dr Somer:** Usually, yes, because an incapable person has to get to your office in some way or another and it usually a relative who will bring that patient in in almost all cases. So that is whom, yes, you would look to to get consent.

**Mr Wessenger:** So you certainly would look for some legislation which would allow you to take those instructions from someone, to give you the legal protection which you do not have now?

**Ms Samek:** In fact, if I might just add a bit, we are looking at legislation that is procedure-specific rather than legislation that is looking at the competency of the person and the mental capacity in all procedures. Normally now we are looking at mental capacity in facilities. Here we are looking at procedure-specific capacity, where the legislation envisions that you may be capable to make a decision here but not to make a decision here.

Those are situations that most practitioners have not had to deal with on an ongoing basis. When the person is deemed to be mentally fit, they are dealing with those in their offices most often. This is procedure-specific and I believe that patients may in fact start challenging the findings of incapacity because you are putting a lot on each individual practitioner.

**Mr Wessenger:** I think it is fair to say you would agree that a patient may have a capacity to consent to one procedure and yet not to another because of the varying levels of capacity. Is that fair to say?

**Dr Somer:** Yes, it is.

**Mr Wessenger:** The other question I have is with respect to a child. As we have been told many times, there are many children under the age of 16 who are capable of making their own medical decisions. Would you agree with that?

**Dr Somer:** Yes.

**Mr Wessenger:** When you have such a child, would you take the instructions of the child to do the treatment?

**Dr Somer:** What age are you talking about?

**Mr Wessenger:** I mean a child whom you deem is capable of making a decision.

**Dr Somer:** Yes, I think you have to talk with him. It is a very personal thing when you are dealing with an individual patient.

**Mr Wessenger:** That is right.

**Dr Somer:** If a patient comes in and you feel that child is capable of making a decision and he says he does not want treatment or does not want this specific treatment but wants something else, you may decide you would provide that treatment or perhaps you may decide you do not want to provide that treatment.

I will give you a for-instance: If a 15- or 14-year-old patient came in and said, "Look, I would like to have all my teeth out because I don't want to be bothered with them in the future," that patient may have the right to make that decision and may be capable of making that decision, but I also have the right to say, "I don't agree with your decision and I won't do it."

**Mr Wessenger:** Right. So you could refer them to another—

**Dr Somer:** I would not refer them anywhere.

**Mr Wessenger:** Not refer them, but you would just say—

**Dr Somer:** "I will not do it."

**Mr Wessenger:** You would refuse to do it. You would exercise your right to refuse.

**Dr Somer:** "You have to find somebody else to mutilate your mouth."

**Mr Wessenger:** But on the other hand, if they wanted to do something that you felt was beneficial for them, you would have no problem in doing it, with a 13-year-old child?

**Dr Somer:** But I would consult with the parent as well. I would try to set it up so that there at least is a consultation process.

**Mr Wessenger:** The reason I have some questions in this regard is: Other health practitioners make decisions and take instructions from children now under the age of 16, particularly in the medical area, and we have had a lot of advice from members of the medical community that they presently, under the existing law, follow the instructions of children under the age of 16 and rely on those instructions. So I am wondering why dentists would take a different position than the medical profession in this regard.

**Dr Somer:** I think, as Ms Samek said earlier, it would be by procedure rather than by an overall consent process. I may accept the decision of a patient under 16 in regard to one procedure and not accept it in regard to another because I do not think that there has been enough consultation or enough information given or the patient has not had time to digest the information for whatever reason.

**Mr Wessenger:** So, in effect, you would be making your own determination of capacity then for that particular procedure?

**Dr Somer:** Not necessarily, but I will want to make sure the patient has all the information. I may decide the patient needs some time to think about it or may need some more information, maybe even from another source; maybe from a second opinion in some cases.

**Ms Samek:** Just to follow up on your comment about physicians, it is my understanding that much of what they talk about centres around, for instance, a child's right to make decisions, a teenager's decision about birth control pills, abortion, issues that are really quite different than we are talking about in the routine care provided in a dental practice. So their concerns are slightly different in that area. We believe that the patient, and the child in particu-

lar, is a component of that family and certainly support the family involvement in the decision-making.

**Mrs Sullivan:** I know we have half a second left for my party. To provide an example from my own family in terms of dental treatment, where a child may well be consulted, I am thinking of the situation where the option may be put before the child whether he or she wants train tracks, head gear, bands, or whatever those other things are, and where the dentist is providing adequate and full information about the use, treatment and ongoing care required from the child, and soliciting advice from the child about which would be the preferable mode of treatment according to that child's own life. The child's preference may well be taken and supersede the decision of the parent, given an equal outcome.

**Ms Samek:** Patient compliance is necessary.

**The Chair:** Dr Somer and Ms Samek, on behalf of this committee I would like to thank you for taking the time out this afternoon and giving us your presentation.

**Dr Somer:** Thank you, Mr Chairman.

**The Chair:** A notice to the committee that the clerk has just handed out a letter from the OMA pertaining to their presentation yesterday.

**Mr Poirier:** This morning.

**The Chair:** Sorry, we lose all sense of time here.

#### OFFICE OF CHILD AND FAMILY SERVICE ADVOCACY

**The Chair:** I would like to call forward our next presenters, from the Office of Child and Family Service Advocacy. Good afternoon. Just a reminder that you will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each caucus. As soon as you are comfortable, please identify yourself for the record and then proceed.

**Ms Finlay:** I am Judy Finlay, manager of the advocacy office.

**Mrs Henley:** I am Kaca Henley, a child advocate.

**Mr Kelley:** I am David Kelley. I am the other child advocate.

**Ms Finlay:** Our presentation today will include the role and the current activity of the Office of Child and Family Service Advocacy and will look at areas of potential service overlap between the advocacy office and the Advocacy Commission. We will speak to our recommendations regarding a system of advocacy specifically for children.

As you are aware, these issues are not only important to your deliberations but they are complex and need considerable attention, more than what is available at this time, so I refer you to our submission. Today I will present the highlights only and hopefully leave ample time for any questions you might have.

The statutory mandate of the advocacy office was given to it by the Child and Family Services Act in 1984 under section 98. Under that, the Minister of Community and Social Services "may establish an Office of Child and

Family Service Advocacy to coordinate and administer a system of advocacy, except for advocacy before a court, on behalf of children and families who receive or seek approved services or services purchased by approved agencies." We also advise the minister on matters and issues and perform any similar functions.

The current activity of the advocacy office is that the office was established actually in 1980, although it was not mandated under legislation until 1984. There are presently three child advocates on staff, which actually were under-resourced because, although we are located in Queen's Park in Toronto, we do provide advocacy services for children throughout the province.

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The advocates have acquired a broad array of specialized skills necessary for child advocacy. Of importance is their understanding of the systems of service for children. That includes young offenders, children's mental health, child welfare, community living, the medically fragile, the physically disabled, the psychiatrically or learning-disabled and the dually diagnosed children. Also, advocates need to understand the developmental needs of children and have clear knowledge of family structure and dynamics.

The types of advocacy our office provides are rights advocacy, case advocacy and systems advocacy. Case advocacy, however, comprises the greatest proportion of service provided by our office and includes situations such as: families are not satisfied with the service they are receiving; there is insufficient flexibility in policies or practice governing the provision of service; there are insufficient resources; there is lack of information; there are complaints against an agency or agency staff; the client or family is unable to articulate the client's needs; there are situations which are complex and difficult to serve.

This is the nature of the cases that our office becomes involved in. The most common intervention strategy we use is to conciliate or mediate on behalf of the client with the service delivery system. Our advocates rarely assume an adversarial approach.

Of note is that 18.5% of our client group are indeed people over the age of 18 so we do in fact, and have been since its inception, working with handicapped adults. We deal with clients who are physically disabled, adults who are developmentally handicapped and adults who have acquired brain injury.

Systems advocacy is achieved through our relationship with the Ministry of Community and Social Services. Our office has a semi-independent arm's-length relationship with the Ministry of Community and Social Services and we report directly to the senior levels of that ministry. We have a neutral alignment with this ministry. This alignment has been maintained and has proven to be effective in the resolution of systemic advocacy issues particularly as it relates to operational activities.

The office is positioned within the ministry in such a way that it can influence and participate in policy development related to children and families. To the fullest extent, however, the office is seen as independent. Advocacy is delivered proactively and free of potential or perceived

conflict of interest in its relationship to this ministry and represents the interests of children and families it serves.

To date we have developed a relationship with other ministries as well. We have developed useful linkages with other ministries to facilitate resolution of case situations regarding rights or case advocacy. The ministries that we have been most active with have been the Ministry of Education, the Ministry of Health or the Ministry of Correctional Services and this on a case-by-case basis only. We acknowledge the need for advocacy services across ministries.

Additionally, advocates have been available for consultation to other ministries, and most recently we have had discussions with two other ministries to develop inter-ministerial protocols for the provision of services through the advocacy office.

That has then been a very brief overview of the activities of the advocacy office. Next I will look at potential duplication and the disparities between the activities of the Advocacy Commission as proposed and those of the advocacy office.

The Advocacy Act is proposing to provide services for vulnerable adults, which will include "those persons 16 years of age or older who are moderately or severely disabled." The Office of Child and Family Service Advocacy is mandated to provide a system of advocacy for children aged 18 or younger. The advocacy office also considers all children to be vulnerable and each referral for service receives a response by an advocate.

As a result, with the creation of the Advocacy Commission there will be two distinct approaches to advocacy for persons 16 to 18. There is the potential for duplication and subsequent confusion for advocacy service providers, referring agencies and service recipients. Protocols need to be established that minimize overlap and confusion and ensure appropriate responsiveness to the consumer.

Second, under the new advocacy system "advocates will be empowered to enter government-funded or regulated institutions in which vulnerable adults reside and to acquire vulnerable clients' records with their consent." This is right of entry and access to files. Advocates from the advocacy office are not provided with the same ability to directly access residences or facilities where children may be in need of advocacy and protection. Unless the child initiates the contact with our office directly, intervention must be sought through the local child welfare authority or ministry officials. Time delays inhibit the immediate response critical for accurate assessment and effective intervention. For example, if a grandmother of a client phones us and is concerned about a child in a child welfare organization, we cannot directly access that child.

Therefore, there would be disparity between the nature and the extent of advocacy services, as they relate to power of access, available for youths 16 to 18 years of age receiving service from advocates representing the Advocacy Commission as opposed to those representing the child and family service advocacy office.

Third, vulnerable persons over the age of 16 seeking advocacy services through the Advocacy Commission will have access irrespective of government affiliation. The advocacy

office provides advocacy for children and families receiving services under the Child and Family Services Act. It is legislated under that act that facilities funded under the Ministry of Community and Social Services must inform all children of the existence of our office. That same kind of accessibility is not available to children in schools, in hospitals or in correctional facilities.

Finally, the introduction of the Consent to Treatment Act will establish the provision of rights advocates for young people under 16 years of age who wish to rebut the act's presumption that they are incapable of making treatment decisions and, in so doing, are eligible for a review board hearing.

Under the Child and Family Services Act, subsection 118(7), the advocacy office is given notice of a child's emergency admission to a secure treatment facility. An advocate from our office goes out to see the child forthwith and we review with that child his or her rights and right to a review.

If both acts are in place as proposed, it appears there will be two sets of rights advocates and two separate review boards. Again, this level of complexity will create confusion for both service providers and children requiring advocacy support.

Finally, our summary and recommendations: Acknowledging these issues and building on the experience in child advocacy that has been gained over the past decade, the advocacy office has identified what it believes to be the prerequisites for a system of advocacy for children as follows:

1. That all children are considered to be vulnerable by nature of their relative powerlessness, and, therefore, each child may require the assistance of an advocate.
2. That all initiatives for children adopt the definition of child stated in the United Nations Convention on the Rights of the Child, and that is, "A child means every human being below the age of 18...." This will ensure consistency in the understanding of and approach to children and influence continuity in the provision of services.
3. That there be a system of advocacy for children that is separate and distinct from the adult advocacy system.
4. That there be equal accessibility across all ministries to advocacy services for children.
5. That the same rights of entry and access to records be available to both adult and child advocates.
6. That accessibility to child advocates be enhanced to accommodate the special needs of the more vulnerable groups of children, such as deaf children, geographically and culturally isolated children, and so on.
7. That there be regional visibility and accessibility to advocacy services for children.
8. The final prerequisite is that the administration of advocacy services for children maintain a semi-independent position with regard to its relationship with the government such that it is unencumbered in its ability to proactively represent the interests of children. However, it must establish meaningful linkages with senior officials within the appropriate ministries in order to influence operational activities and participate in policy development as it relates to children.

To implement a system of child advocacy based on these prerequisites would necessitate broad philosophical, structural and legislative changes. Economically, this may not be achievable at this time. Recommendations have therefore been developed to reflect those short-term and long-term goals.

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Recommendations achievable in the short term:

1. That access to children who may require advocacy services be enhanced by empowering child advocates, through the advocacy office, to enter residences and facilities as required. This may be achieved through non-legislative changes to existing structures and mechanisms.

2. That interministerial protocols be developed between the advocacy office and those ministries which have primary responsibility for children in order that there be provision of advocacy services to the majority of children receiving government services.

3. That the advocacy office continue to provide a range of advocacy services to children between the ages of 0 and 18.

4. That the advocacy office continue in its development to address issues of staffing, visibility and accessibility.

5. That the Advocacy Commission, early in its deliberation, take steps to minimize confusion created by duplication in advocacy services provided by the commission and the advocacy office.

Our recommendation for the long term is that there be a single system of advocacy for all children 0 to 18 years of age in Ontario that ensures accessibility and provides a full range of advocacy services.

Thank you.

**The Chair:** Thank you. Each caucus has about five minutes for questions and comments.

**Mrs Sullivan:** I think your brief really underlines some of the reasons we have called for the withdrawal of these bills and redrafting. There is substantial overlap. The work of your organization in terms of child advocacy is one that has been useful in the past—I would like to see it expanded—but what is of concern is that with duplication of services there would be confusion that would lead to a deterioration rather than an improvement in the service. You have identified those kinds of issues in terms of overlap, and of course there are overlaps with other services provided by other agencies as well. We certainly feel that a major redraft is necessary and then further consultation to ensure that apparent problems are indeed cleared up.

I want to ask you in particular about the case management advocacy that you do. Because there is no definition of the advocate's role in this act, I was very unsure whether case management advocacy is envisioned here.

I would also like to ask you about how you interface with other volunteer advocates who are included in Bill 74 as part of the advocacy structure.

**Mr Kelley:** To clarify a bit, we try not to become case managers. We try to support the community-based groups or volunteer groups, to be the people who do the ongoing case management. Our role is ideally short-term, to try to go in and deal with the issues people are bringing forth,

because we cover the whole province and there are three of us.

We have quite a good working relationship with people who provide advocacy on a volunteer basis, whether as individuals or as a group. There are times when people who are working from within the system can achieve some things that cannot be achieved by people who are working from outside and vice versa. So we try to support them in doing things they can do that we may not be able to do, being civil servants, when it would achieve the results that would be best for the client.

**Mrs Sullivan:** We have had testimony before the committee that has been quite emphatic that people who work within the system are unable to provide adequate advocacy services for vulnerable people. Would you respond to that?

**Ms Finlay:** I think we did respond to it in the submission, but our experience has been that if we are able to maintain an arm's-length relationship with the government, we can be proactive in our support of those for whom we are advocating.

What we find most useful by being within the system at the same time is that we have direct and regular linkages with senior officials, particularly in the Ministry of Community and Social Services, and we are regularly able to have input with regard to policy development and operational management.

We find that extremely useful, and we have taken this into account many times when we have reviewed our own practices and our own positioning within the ministry. We wonder whether we would have the same abilities to be able to influence policy if we were outside the system.

**Mrs Sullivan:** Could I just have a chance for one last question? It is a very short one. Do you ever link up with or discuss the process of advocacy and cross-system needs with the psychiatric patients' advocates?

**Ms Finlay:** No.

**Mrs Henley:** Yes, we do.

**Ms Finlay:** I said no, she says yes.

**Mrs Henley:** We have been working with them on an ongoing basis. We have met with them, we discuss with them, and many times we will have a case that we will call them on if there is a situation where they might know somebody or might know something. We do work with them.

**Mr Kelley:** It is usually case specific, so Judy may not have had some cases that dealt with that, but we have.

**Mrs Henley:** Judy is fairly new.

**Ms Finlay:** I am new to the office.

**Mr Carr:** I was interested in just relating to the number of calls. I know the brochure that got sold, because I know it says Charles Beer is the minister.

**Mrs Sullivan:** We would like to keep it that way.

**Mr Carr:** Unless he crossed the floor, I do not think he is minister. It said there were over 125 calls per day, and you have three advocates. Is that what you are at now, or what are you getting now in terms of the number of calls?

**Ms Finlay:** We probably get that many calls per day. In terms of the number of cases, under the child advocacy part of our operations we average roughly 500 cases a year. Those are full-blown cases. We get probably that many calls for information and consultation, however, if there are three of us.

**Mr Carr:** I know it is difficult to say what is going happen, but if we work on a case management type of system, knowing that we have 230-odd hospitals and 1,000 nursing homes and so on, from your best guess—and again you are not doing exactly the same work and you do not know—how many would we need, would you say, to handle the situation if the legislation goes through?

**Ms Finlay:** For just children?

**Mr Carr:** No, for the entire legislation.

**Ms Finlay:** I have no idea. I could speak to children, but I do not think—

**Mr Carr:** That is the problem we have. Of anybody, you are our best guess at this, and you cannot even guess at it.

**Mrs Henley:** The problem we have is that we are—

**Mr Carr:** Just quickly, I will finish. That is a case where we are looking at it and you are the pros. You are the best we have when it comes to advocacy, such as it is today, and yet you cannot tell us, based on the facts. I am sorry, go ahead.

**Mrs Henley:** Part of it has to do with visibility. Who knows about us? Our situation is such that there are many kids and many families out there who very much need our services, and when they find out about us they say, "How come we didn't know about you?" It is very hard for us to tell because it depends on how widely you are known and how many people there are who need you.

**Mr Kelley:** Also, there are different systems that use the case management model, so I would try to get as close to a ballpark figure as possible. If you were to take a look at the average case load of an adult protection services worker and of a child welfare worker and then average those out, that might give you a ballpark figure.

**Mr Carr:** That is why it has been so difficult taking a look at this overall thing, because we put all these things in place. We put support and custody in place and then a year later we needed to add more people. We are continually wrong about it, for whatever reasons.

There is just one other thing you touched on and the Ontario Medical Association talked about this morning. One of the reasons a lot of legislation is put in place is to control, to have checks and balances. They were a little bit concerned there would be no checks and balances on the advocates. Having been involved in this for a period of time, what do you say would be the best method to oversee the advocates? How would you like to see it if you had your choice? None of the above?

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**Ms Finlay:** It is a difficult question. What we are viewing for ourselves right now is the opportunity to have something like a commission or an advisory board that we would report to. I report to senior levels of government,

but because of our position of being at arm's length they do not supervise us in regular kinds of ways. What I think would be worth reviewing for us is an advisory group or an advisory commission of sorts with representations from the consumer groups we serve as well as representations from the ministries we serve. That would be useful for us.

**Mr Carr:** So the final authority would be something arm's length. You believe you need that?

**Ms Finlay:** Yes.

**Mr Carr:** Okay, thanks.

**Ms Akande:** I was interested in your recommendation of a semi-independent position of the child's advocate, and I was wondering if you would comment if in fact that is not a system that does not promote change, that really does continue to promote the status quo.

**Ms Finlay:** Being relatively new since September, my experience has been that in fact we have again been able to influence change in terms of operations within the Ministry of Community and Social Services and policy development. So from my position or from my perspective, I have seen us as being able to motivate change and facilitate change as well. But in terms of how clients view us, I think we need that arm's-length positioning so that they see us as being very independent of the government.

**Ms Akande:** Let me be direct. Do you think there are instances where your intervention is necessary, but even your minor relationship with the government prevents people from calling upon you? Of course, you would be the last person in a position to know that. That has been a statement that has been made. Could you perceive of there being any difficulty with that?

**Ms Finlay:** It is conceivable, but there are an awful lot of people who call us. There is another thing I meant originally to add when we were talking about being inside the ministry or outside the ministry. One of the advantages of being inside the ministry is we are known, our skills are known, our abilities are known; we know the people in the individual area offices, program supervisors, and we deal with them frequently. That improves our ability to act and to make things happen, and we are trusted. We are deemed to be part of the ministry by the ministry people, and they work with us rather than against us. It does not turn into an adversarial thing.

**Ms Akande:** I would like to express, if I may, some concern about the fact that the relationship also has an effect of not allowing for or encouraging that permanent change; an acquiescence of how to deal with the situation today rather than a motivation to change the situation so that it may not occur tomorrow. I use the example of the number of repeat situations, repeat clients that you have to deal with around the same issues, even within the ministry.

**Ms Finlay:** Again speaking from my experience, when we have a cluster of clients or if we have repeat clients who are frustrated in their consistent efforts to receive service, then I bring forward those issues to the senior levels of government, those specific issues looking for changes within policy or operations. In the few that have been brought forward, I know I have been relatively suc-

cessful at achieving change either for the client or addressing issues related to groups of clients. Do you want to speak to your experience?

**Mrs Henley:** We have had influences in certain areas. We had a lot of head-injured cases, and in the end there were some changes made in the system to help the head-injured. We were heard on the issue of the dually diagnosed, and some movement has been made in that area as well. So we have had some effect.

**Mr Kelley:** On an individualized basis, we often get the people who are frustrating everybody in the system or in that particular town or whatever. Often to expect that the situation is going to resolve itself for a long period of time or permanently over a short period of time is somewhat unrealistic in terms of what we can achieve. But often people find having somebody who is not part of the local system involved in trying to mediate and support some shift in what is happening currently to be very supportive. I agree with you that there are some clients we are working with, whether it be an individual or a family, who are probably going to pop up over and over again.

**The Chair:** Ms Finlay, Mrs Henley and Mr Kelley, on behalf of this committee I would like to thank you for taking the time out and giving us your presentation today.

#### PLANNED PARENTHOOD OF TORONTO

**The Chair:** I would like to call forward our next presenters, from Planned Parenthood of Toronto. Good afternoon. I would just remind you that you will be allowed a half-hour for your presentation. The committee would appreciate if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you comfortable, please identify yourself for the record and then proceed.

**Mr Daschko:** My name is Alex Daschko. I am a member of the board of directors for Planned Parenthood of Toronto and also the chair of its social affairs and public issues committee. Beside me is Marion Maye, who is the coordinator for the clinic, which is known as the House of Planned Parenthood, in Toronto. In the audience we have Terry Fallis, who is the chair of Planned Parenthood of Toronto, and Evelyn Kent, who is our executive director. I think we will start our presentation now.

**Ms Maye:** Stephen and Joan had been having sexual intercourse for almost a year and using condoms sometimes. Joan had been told by her family doctor that since she was a minor, she could not get the birth control pill without her parents' consent. They came to our clinic when Joan thought that she might be pregnant.

Jasmine was a 15-year-old high school student who had been sexually assaulted at a party. She was not supposed to be at the party and so was afraid to tell her mother what had happened. She delayed six months before coming into our clinic to seek medical treatment and counselling. Her reason for the delay was that she was afraid her mother would find out what had happened and kick her out of the house.

Julie was a 14-year-old girl who lived at home sometimes. She came to our clinic complaining of vague

abdominal pains. Subsequent testing proved that she had chlamydia, a sexually transmitted disease that, if left untreated, can cause pelvic inflammatory disease and possibly infertility. She did not believe she could get a sexually transmitted disease, because she did not sleep around.

Sonja had just turned 16 when she came to our clinic for a pregnancy test. The test itself was somewhat unnecessary; she was obviously pregnant, in fact six and a half months pregnant. Sonja did not want to be pregnant and so had denied her condition. She told us that neither her parents nor her teachers had made any comment to her about the pregnancy. Her alternatives were now limited, and her need for prenatal care was imperative.

These scenarios are not fictitious, but rather reflect just some of the cases Planned Parenthood of Toronto deals with on a regular basis.

**Mr Daschko:** At this moment, we would like to give you some background describing who we are and what we do.

Planned Parenthood of Toronto is a community-based voluntary agency whose purpose is to promote the health and wellbeing of individuals and the community by encouraging and facilitating responsible and informed decision-making with respect to healthy human sexuality. This is achieved by the provision of primary health care, education, counselling and information services for individuals and groups of all ages, and by the provision of informed social comment and appropriate research. These activities are provided by a large number of trained and dedicated community volunteers and a small multidisciplinary professional staff.

Although young people under 16 years of age do not make up a large percentage of our clients, those who do use our services are often at highest risk and are often the ones who delay seeking help. This is our reason for speaking before you today. Specifically, we wish to express our concerns over certain provisions of Bill 109, the Consent to Treatment Act, 1991.

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On the whole, we recognize the intended positive spirit of the proposed legislation, that is, to respect people's rights to consent when capable and to provide protection that safeguards their best interests when they are incapable. However, we strongly believe that for all its good intentions the proposed legislation will set an antagonistic environment of fear for those involved, for people under 16 who wish to obtain confidential counselling and, on the other hand, for professional health care workers.

This standing committee has no doubt been presented with a series of statistics demonstrating the health concerns of people under 16 years of age and their need for professional confidential medical advice. Without diminishing the value of any of these statistics, we wish to highlight those that have a direct bearing on our organization. For example, statistics demonstrate that 31% of male and 21% of female grade 9 students have had sexual intercourse at least once. That figure increases to nearly one-half of grade 11 students who have had sexual intercourse at least once. In a 15-year span between 1975 and 1989,

pregnancies in Canada for adolescents under 16 have averaged approximately 476 per year, reaching a high of 646 in 1979.

Fortunately these figures have been steadily declining in recent years. The reason for this, as one report suggests, is "expanding sexuality education, expansion of birth control services operated by health units, and an increased willingness by physicians to cope with the sexual needs, in a confidential manner, of young people."

The rate of sexually transmitted diseases in adolescent females in Ontario between 10 and 14 years of age, specifically gonorrhoea and chlamydia, has been fluctuating during the same 15-year period. There has been a recent upsurge in antibiotic-resistant strains of gonorrhoea. Chlamydia also poses a real danger in that it produces very mild symptoms, if any at all. This is why it often goes undiagnosed. Without medical treatment, it can result in ectopic pregnancies. As one report points out: "The rate of ectopic pregnancy due to chlamydia in Canada has been increasing through the 1980s. Untreated chlamydia infection is also established as a major cause of infertility."

In Ontario, as of December 1991, there were 126 people who were HIV antibody positive in the 16-to-19-year-old age group. In the next category, the 20-to-29-year-old age group, there were 3,196 young people. Six people have already developed AIDS in the younger age group, and in the 20-to-29-year-old group, 407 people have developed AIDS. Since it is believed it takes between five to 10 years to develop AIDS after contracting the virus, we can assume that some of these older individuals became HIV positive while still in their teens. Some of these people would have been recipients of contaminated blood or blood products. However, most of these people contract the HIV through sexual contact or injection drug use.

Having established that a significant number of people under 16 are sexually active and therefore at risk of unplanned pregnancies and sexually transmitted diseases, it is also equally imperative to consider the importance this age group places on access to confidential medical assistance. One survey suggests that over 80% of high school students have a strong concern for privacy and confidentiality from their doctors. The clients at our community health centre tell us this is the number one reason for using our clinical services.

Unfortunately, none of these statistics demonstrates the number of people in this age group who refuse to seek medical assistance due to their fear of non-confidentiality, even under present circumstances as we know them. Such fears may currently be based on rumours, myths, street corner and locker room advice. Anything that further undermines whatever trust this age group places on the current system could lead to tragic consequences. To this end, specific aspects of Bill 109 will further such fears and consequences.

As submitted earlier this afternoon, Planned Parenthood of Toronto recognizes the need to respect people's rights to consent when capable and to provide protection that safeguards their best interests when they are incapable. However, Planned Parenthood of Toronto strongly objects to the arbitrary designation of any age as a criterion

to determine capacity to consent with respect to treatment. The proposed legislation, in subsections 8(1) and 8(2) and section 10, stipulates a benchmark of 16 years of age.

However practical it may seem, any arbitrary measure is at least counterproductive and at worst fatal. The reason for our objection is primarily threefold: (1) people mature at different ages, (2) an environment of confidentiality must be preserved in order to facilitate and encourage young people to seek help, and (3) we must provide the freedom and environment for health care professionals to do their jobs properly.

Dealing with our first concern, maturity and consent, it should not come as a surprise to anyone that maturity cannot be designated at any particular age. Many people under 16 are mature enough to provide informed consent to treatment. On the other hand, there are those older than 16 who are incapable of providing informed consent. Consideration must also be given to the type and complexity of treatment. All of these factors have a bearing on an individual's ability to provide informed consent. Therefore, the obvious determinant for an individual's ability to provide consent must be assessed on its individual merits in each case. For example, an individual's recognition of a health problem, and the initiative in seeking help, provides some evidence of competence. Judging each case on its individual merits may not be the easiest method, but in the long run we believe this is the best method for all concerned.

Regarding the issue of confidentiality, it is essential to maintain a high degree of confidentiality between the health care worker and the client, regardless of age. A strong sense of trust and confidence is the basic ingredient in providing thorough diagnosis and appropriate treatment. Without this environment of trust, the client may not even seek professional assistance.

The issue of the fear of litigation in the minds of health care workers under the proposed provision of the legislation must be considered. Under the legislation it would be much easier for a health care worker to assume that any individual under the age of 16 does not have the ability to make an informed decision. Fearing litigation from parents, we believe the health care worker may not attempt to rebut the assumption of incapacity and may therefore refuse whatever treatment is necessary.

In summary, because of our concerns with the proposed legislation, Planned Parenthood of Toronto wishes to recommend to the standing committee on the administration of justice that any reference to an arbitrary age be removed from the legislation. We believe that the best and most enlightened course of action would be to continue the current practice, that we allow the common law criteria to continue to determine each individual case on its own individual and unique merit. This is by far the superior route to take, in that it provides justice and assumes responsibility for all those who provide and seek service.

Finally, we would like to thank this particular committee for allowing us to express our concerns on this particular issue today.

**Mrs Sullivan:** This is a useful brief. I should tell you that several other organizations, including public health officials, have appeared before the committee and expressed

the same concerns that you have in relationship to counselling, education and advice on sexuality and STD matters. I think it is fair to say that the Minister of Health has signalled that there will be amendments coming forward. We had hoped we would be able to see those amendments during this public hearing process so that there could be a judgement and comment made on the efficacy of those amendments. However, the government has refused to do that.

There is, I think, all-party concurrence with respect to the age matter. Bill 109 speaks about a health practitioner as a person who is registered under a licence—the government has not been able to tell us who in fact they are going to include in this schedule—or a person who is a member of a prescribed category. We would assume, although the government has not told us and appears not to know yet, that those people who are going to be described as health practitioners may indeed include counsellors and may include social workers and people who are providing a counselling service that is related to health care, whether it is nutritional or whether as in your case, it relates to sexual and birth control planning issues.

I wonder if you have examined the acts from the point of view of your staff being affected as health practitioners under the acts, and indeed where you might see problems in terms of delay if the person with whom you are dealing is considered to be incapable of making a decision on his own behalf.

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**Ms Maye:** I am not sure I understood your question at the very end.

**Mrs Sullivan:** You may have a situation where a person may have a developmental difficulty who, in the course of counselling you would provide, would be directed to that person at a level of understanding for that person. Given the kind of delays that could occur under this act, which other health care practitioners have pointed out as being a serious matter of concern, in your particular area of counselling would you see that as a difficulty?

**Ms Maye:** Certainly that is a concern. The type of treatment, the type of counselling we do is not usually urgent or needing immediate attention. I think the real problem for us is not being able to make that decision whether this person is competent to decide and having age make it for us. Certainly our doctors are willing to rebut that. What this bill does not tell us is how they are to do it specifically and what may happen if a parent does come in and does feel the doctor has made that assumption wrongly and wishes to press charges. We do not know how to defend ourselves.

A bigger concern is that there are physicians and health care workers out there who are already refusing to treat minors and are not seeing them. Those are the people who are coming to us. You mentioned the concern about who this does affect, and we are concerned about who this does affect if it goes through. We have counsellors. We have a social worker. Are they included in this as health care professionals? They are not registered. You are quite right to say that is also a concern of ours.

**Mr J. Wilson:** Thank you very much for your presentation. As you know, the Ontario PC Party has put forward an amendment to deal with the age issue and I am grateful to hear from Mrs Sullivan that now has all-party concurrence.

**Mrs Sullivan:** There was before you put your amendment on the table.

**Mr J. Wilson:** There was not. At least we put our amendment on the table, but it is nice of you to say so. I always have to go after Mrs Sullivan in two senses: I also follow her in terms of speaking order all the time.

I think what Mrs Sullivan might have been getting at, and she might shoot me for this, was that in your setting an advocate may have to be called in in the scenario Mrs Sullivan was talking about where you find an incapable person before you. You have really not talked about Bill 74, the Advocacy Act. It seems to me you people do advocacy but you may be having another government-appointed advocate come in. Do you have any thoughts on that bill and its effect on your daily routines?

**Ms Maye:** I have read the bill, but certainly not in depth. I am not convinced it will affect us to any great extent. I have been at the clinic almost six years full-time and part-time now. I have not yet come across anyone under 16 who has come to us and not been able to make a decision or who we have not felt has been competent. The fact that they make it to our clinic and the fact that they know why they are there and what they want proves they are somewhat competent to make that decision.

There have been times when we have asked clients to go away to think about a decision whether or not we want to treat them, but we have never had to refuse based on the fact we did not feel they were competent. Certainly at all times we would also ask them to bring in their parents, especially the younger ones. It is the rare client who comes to us willing to bring in a parent.

**Mr J. Wilson:** That makes sense, that in your setting you are just not seeing incompetent young people. If you got rid of the age discrimination there you would be all right.

**Mr Daschko:** I think it is also important to underline, although we did not state it in our brief—it is almost a given—I think it is important to state for the record that in a lot of these situations when a person is under 16 years of age, Planned Parenthood of Toronto would of course encourage her to go through the family and to use the family support system that could be in place. But in a lot of situations that support is not there, either because the guardian or the adults do not know how to deal with the problem or because they may react in such a way that could terrify the person in question. Obviously in those circumstances and situations we feel the confidentiality aspect is very important.

**Ms Maye:** There are already exceptions to this confidentiality that we follow, and we did not put this in. But certainly in cases of abuse of minors, whether that be sexual, emotional or mental, there is a law already there and something that we already follow. While we are very concerned with maintaining confidentiality, we tell our clients that there are exceptions to this.

**Mr Wessenger:** I would just like to advise you that certainly our ministry has no intention, there are no plans and we are not even considering bringing social workers and counsellors under the definition of health practitioner under this act. I will just ask the question: Do you want us to consider doing that?

**Mr Daschko:** It sounds like a loaded question.

**Mrs Sullivan:** At least we know one of the answers.

**Mr Daschko:** At this point I think it would be difficult for us to respond on that basis because I am not even sure, considering the type of staff we have and so forth—I do not know.

**Ms Maye:** Most of our counselling is giving of information. It is not directive counselling; it is informing clients. It is giving them information they may need to have. I am not convinced that even if this was to go through for counsellors and social workers it would have a great deal of impact on what we do at our clinic at the present time.

**Mr Wessenger:** I want to assure you that we do not think it is appropriate to have counsellors and social workers covered under this legislation as health practitioners.

**Mr Poirier:** Tell them the good news about age 16.

**Mr Wessenger:** I think you have heard the indication about the age of 16. We have not heard a presenter make a position other than to say the age 16 should go, so I think that is a pretty good assurance to you.

**Mr J. Wilson:** Why do you not give us your amendments?

**Mr Wessenger:** You have to relax. We might vote for yours, Jim.

**Ms Maye:** The question, I guess, for myself would be, is there going to be an age, or have you decided to not have an age at all, if you have decided unanimously that 16 should not be it?

**Mr Wessenger:** Let me just say that every presenter has recommended there be no age and that we use the common law position. We have not heard anybody ask for another age.

**The Chair:** Mr Daschko and Ms Maye, on behalf of this committee I would like to thank you for taking time out this afternoon and submitting your brief to us.

The committee adjourned at 1628.

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Spinks, Trudy, Ministry of Citizenship

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Friday 13 March 1992

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Le vendredi 13 mars 1992

## Standing committee on administration of justice

Advocacy Act, 1991,  
and companion legislation

## Comité permanent de l'administration de la justice

Loi de 1991 sur l'intervention  
et les projets de loi  
qui l'accompagnent

Chair: Mike Cooper  
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# LEGISLATIVE ASSEMBLY OF ONTARIO

## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

Friday 13 March 1992

The committee met at 0945 in committee room 1.

### ADVOCACY ACT, 1991, AND COMPANION LEGISLATION LOI DE 1991 SUR L'INTERVENTION ET LES PROJETS DE LOI QUI L'ACCOMPAGNENT

Resuming consideration of Bill 7, An Act to amend the Powers of Attorney Act; Bill 8, An Act respecting Natural Death; Bill 74, An Act respecting the Provision of Advocacy Services to Vulnerable Persons / Projet de loi 74, Loi concernant la prestation de services d'intervenants en faveur des personnes vulnérables; Bill 108, An Act to provide for the making of Decisions on behalf of Adults concerning the Management of their Property and concerning their Personal Care / Projet de loi 108, Loi prévoyant la prise de décisions au nom d'adultes en ce qui concerne la gestion de leurs biens et le soin de leur personne; Bill 109, An Act respecting Consent to Treatment / Projet de loi 109, Loi concernant le consentement au traitement; and Bill 110, An Act to amend certain Statutes of Ontario consequent upon the enactment of the Consent to Treatment Act, 1991 and the Substitute Decisions Act, 1991 / Projet de loi 110, Loi modifiant certaines lois de l'Ontario par suite de l'adoption de la Loi de 1991 sur le consentement au traitement et de la Loi de 1991 sur la prise de décisions au nom d'autrui.

### NATIONAL COUNCIL ON BIOETHICS IN HUMAN RESEARCH

**The Chair:** I call to order this meeting of the standing committee on administration of justice. I would like to call forward our first presenter, from the National Council on Bioethics in Human Research. Good morning. I would just remind you that you will be allowed a half-hour for your presentation. The committee would appreciate if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, please identify yourself for the record and then proceed.

**Ms Miller:** Thank you for the opportunity to meet with you today to discuss the proposed Bill 109, the Consent to Treatment Act. My name is Judith Miller and I am the founding director of the National Council on Bioethics in Human Research. The mandate of my organization, which is described in the materials you have in front of you, is to promote high ethical standards for health science research with human subjects through consultation and advice to local multidisciplinary research ethics boards.

I have been personally and formally involved in research ethics for close to 10 years. In 1983 I joined the Medical Research Council of Canada, where I helped revise the council's Guidelines on Research Involving Human Subjects. In 1987 I coordinated an International Summit Con-

ference on Bioethics, which focused on developing international standards for research with human subjects. More recently, I was involved in redrafting the International Guidelines for Biomedical Research Involving Human Subjects prepared by the Council for International Organizations of Medical Sciences, which is affiliated with the World Health Organization. Now in my position as director of NCBHR, affectionately known as "NC Bear," I assist local research ethics boards in interpreting and applying the research standards set out in the MRC guidelines.

Today I wish to examine with you two areas of the bill. Since I shall do so from quite different bases, I shall treat the areas separately and divide my presentation into two distinct parts.

First, I wish to examine with you, on behalf of NCBHR, Bill 109's position on research with individuals unable to give consent, section 15, and the designation of individuals who speak on behalf of incapable people, section 16. Both sections would have major impact on health sciences research in Ontario.

I shall start with section 15 which, as written, prohibits research with individuals unable to give consent. By juxtaposing research with nontherapeutic sterilization, paragraph 2, and transplantation, paragraph 3, section 15 links research with two illegal procedures. As Professor Bernard Dickens noted in his brief to you on February 12, this juxtaposition implies the illegality of research involving a person who is incapable of consent. As drafted, this article would seriously impede much needed research for the benefit of vulnerable individuals.

Two years ago, NCBHR was asked to review the concerns of researchers, physicians, lawyers and the public about research involving children. In response, NCBHR, collaboratively with the Canadian Paediatric Society, formed a task force on research involving children. The task force conducted its investigation for two years and has recently completed a report entitled Research Involving Children. The positions in this report diametrically oppose section 15. The report affirms that the ethical principles of justice and of doing no harm are as fundamental as consent. It argues that there must be justice for children in the pursuit of research. The decision for or against a child's participation should be determined by parents, presuming the research has been approved by a research ethics board as scientifically and ethically valid. The assent of the child should also be sought where possible.

Members of the task force concluded that excluding from research those who cannot give consent causes them harm by denying members of these groups the benefits of research which could improve their care and chances of recovery. It is unethical and scientifically invalid to apply to sick persons treatments that have not been investigated. The task force argues for research with children on both

ethical and legal grounds provided that the research questions are formulated in scientifically and ethically sound protocols and can only be answered by involving children.

You have received at the back of my brief a short article describing the task force report and I will leave this advance copy of the complete report with Lisa Freedman or someone here to distribute to you. I will also leave biosketches of the members of my council in case you are interested. We welcome your comments on the report and shall be seeking wide public discussion to refine this document. My text refers to particular sections relevant to our discussion of section 15: sections on the nature, benefits and importance of research with children; the ethical rationale for research with children; recommendations, including new procedural safeguards suggested for protection of children who serve as subjects.

In keeping with the task force report, support for research with vulnerable groups characterizes guidelines developed in Canada and other countries. As Dr Eric Meslin pointed out in his presentation to you earlier, since 1975 every major international and national code of research ethics has permitted the involvement of patients who are unable to consent, provided rigorous conditions are followed. In the Canadian system of ethics review of health science research, these conditions are applied by conscientious investigators working in concert with independent local research ethics boards that must review and approve research protocols before they can be conducted. Conditions include that the research be scientifically important, that it be impossible to conduct the research on patients who can consent, that it is likely that the benefits to the research subjects outweigh the impositions on them, and others listed in my text.

Among the 40 recommendations of the task force, the summary article draws your attention to three major points on page 3 of the article. Please take the time to consider these and all the task force recommendations in context. They propose many procedural safeguards that merit your attention as you examine legislative options.

It is the work of the national council to support and encourage research ethics boards in applying standards outlined in the MRC Guidelines on Research Involving Human Subjects and in maintaining high ethical standards for research. The Canadian system of ethics review relies on the assessments of these local boards to ensure that community values are respected in weighing the acceptability of proposed research and that those in a position to monitor the research on a continuing basis are responsible for its approval.

In light of existing protections and the importance of research involving persons unable to give consent, the National Council on Bioethics in Human Research joins with Professor Dickens, Dr Fred Lowy and Professor Eric Meslin, all of whom presented to you on this point, in recommending that paragraph 1 of section 15 be omitted from Bill 109 and that the bill specify that, "Nothing in this act changes the law affecting a medical procedure whose primary purpose is research proposed on a person who is incapable of consenting to the procedure."

Further, I wish to draw to your attention section 16. Even if paragraph 1 is removed, the implications for research of section 16 are profound. This section seems to require that consent be sought primarily from a legal representative or advocate rather than from a family member, even when there is no evidence that a family is not acting in the best interests of the individual. This procedure poses practical and philosophical difficulties.

Consider for a moment the instance of a three-year-old child who is eligible to participate in an ethically and scientifically sound study to test the effectiveness of one treatment against another. Is it reasonable to ask a physician-investigator to verify whether a guardian had been appointed under the Substitute Decisions Act, to find out whether there is an attorney for personal care under a power of attorney, to inquire whether there is a representative appointed by the Consent and Capacity Review Board, and all these before seeking authorization, for research with the child, from the parent who accompanied the three-year-old to the office? The net effect of section 16 will be to exclude children and other vulnerable populations from research.

I am well aware that the issue of consent for incapable subjects is ridden with legal and ethical conflicts. At the same time, I have learned from experience in research ethics that it is possible to create sound and tried standards and mechanisms at the local, national and international level to ensure the ethical conduct of research with human subjects. Controls to achieve consent and respect are hard to draft into legislation that helps achieve an appropriate balance between short-term protections for the individual and long-term benefits for both the individual and society. Despite its strengths and admirable goals, the bill as proposed could result in serious harm.

The Ontario Minister of Health has noted that she plans to deal with medical research with individuals unable to consent separately from Bill 109. Should she do so, the National Council on Bioethics in Human Research would be pleased to collaborate in this work.

Now I want to turn to the second part of my presentation, the measures of Bill 109 and of Bill 74, the advocacy bill, related to consent for treatment for psychiatric patients. While I have professional views on these matters, I am speaking here in a personal capacity, from the heart, not as a representative of any organization. I will speak with you from painful experience about matters that are extremely hard to live through and also hard to convey if you have not experienced them directly. The potential detrimental impact of your bills is too serious for me not to share with you some personal and private experiences to give you at least a small window on the harm Bills 109 and 74 could cause.

Let me recount for you a few real instances to show you how even the current Ontario Mental Health Act frustrates those who seek to help patients and how the intended added protections of Bills 109 and 74 will worsen an already difficult situation. As I recount my experiences, I shall refer to several provisions of your bill, namely, subsections 13(2) and (3), which give precedence to any expressed wish of the individual unless that individual has

been formally declared legally incompetent, and sections 10, 16 and 20 of Bill 109, which require advocates, legal hearings and significant delays in any treatment of incapable patients unless they are emergency measures to prevent imminent serious bodily harm. I shall speak briefly also to the very narrow limits in the way the criteria for emergency treatment, subsection 22(1), are often applied and interpreted by doctors, hospitals and courts.

For me, the most disturbing element of the proposed bill for consent to treatment is section 13. This section honours the momentary wishes of a patient to refuse treatment.

The proposal is problematic in the context of personal experience with a loved family member with psychiatric illness. When my son is ill, he may recognize that he has a problem at the early stages of an episode. He has asked on occasion, for example, to be taken to hospital. As he becomes less well, he denies there is any problem and therefore any need for treatment. Frequently, when ill, he becomes paranoid and believes that medications are poisonous. A large part of effective treatment is bringing about his awareness and acceptance of his illness and the need for treatment.

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I am told by health professionals, and have certainly seen in my interactions with other patients in hospital, that this is not an uncommon sequence of events. It typifies numerous conditions including, for example, manic depressive illness, schizophrenia, anorexia nervosa. I am not saying anything more here than Alcoholics Anonymous says, things that AA, you and I know are true. While someone who is mildly alcoholic or mentally ill may be willing to seek treatment, those more severely afflicted will deny the problem. The first step of the AA credo is recognition of the illness, and an integral part of their approach is that an alcoholic often cannot do this alone. The same is true for mental illness.

When becoming ill, my son may be rational and relatively clear for a few minutes, and then quite irrational and disconnected. You may believe this is no problem under the Mental Health Act or under proposed Bill 109, that someone in this state expressing wishes not to take medications would receive needed treatment because the person would be legally incapable and someone would speak on his behalf and in his best interest. The reality experienced is far from this.

Incapacity, in practice, seems to be defined by extremely limited boundaries. Thus, for example, when my son was reporting a series of imaginary murders to the police and requesting their protection from imaginary people he thought were after him, when he had not eaten anything for days because he thought food was poisonous, when he was living in an apartment where the toilet had been plugged for weeks because he would allow entry to no one, including a plumber—and I did sneak in once when he was out and leave some food, hoping he would eat it—he was not considered incapable or certifiable, nor admitted to hospital. Nor would he, at this stage of his illness, admit to being ill.

Bill 109 would make the situation even worse. It would require honouring a momentary wish expressed by some-

one in this state not to have treatment that could bring him back from what even he considers a nightmare. Subsections 13(2) and 13(3) were probably drafted with someone not mentally ill in mind and intended to respect last-minute changes of mind about treatment or no treatment. Of course there must be a way to respect these and to respect the wishes and needs of the mentally ill as well. I argue that the general provisions here are dangerous and harmful for the psychiatric patient and must be changed in the best interest of these patients, their families and, ultimately, society.

I also ask you what is respect for a psychiatric patient? Is it taking a momentary wish, even of someone in a somewhat deranged state, as a definitive guide? Bill 109 might condemn people like my son to imprisonment within their illness, and it is a prison. Imagine a state where you cannot sit still, where your brain keeps firing disconnected thoughts so that when you start a sentence your mind flits before you complete it, where you hear voices in your head that are louder than those outside.

In his last illness episode, my son broke four pairs of glasses because he could not stand the things he was seeing. It took him months of struggle to realize it was not the glasses at fault but his illness. Mental illness is hell for the people involved, both patients and their families. When ill, my son has repeatedly indicated he did not want medications, yet he has also expressed enormous relief and gratitude when the medication stilled the hallucinations and allowed him to reconnect his thoughts and pick up the disrupted fragments of his life. The law must give health care providers the scope to treat those in need.

Let's turn now to proposed provisions for advocates. Please imagine for a moment that after weeks of worry about what is happening to your child, the agony he is experiencing, you finally manage to convince him to go to the hospital, a safe environment where treatment is available. With the proposed legislation, if I have understood it correctly, treatment would not be available for the incapable without significant delays until an advocate, a stranger who does not know the patient or his history, had talked to him about his rights to call a board to obtain legal services and to refuse treatment until the board and possibly an appeal are completed. Scared and confused in the first place, so advised, my son is extremely likely to refuse treatment.

The advocacy system, as proposed, is likely to build barriers to access to care for the incapable. It is also likely to prove difficult to find competent advocates and to monitor that the system is working.

The often burdensome and important role of family members and health service providers who exercise their best judgements, based on care for and experience with the patient, must not be supplanted, as called for in section 6 of Bill 74, by an elaborate system of neutral advocates who remain strangers regardless of how well intentioned they are and how many personal experiences with disabilities they have had.

Surely clear evidence of concern in the particular case, at least a suspicion of neglect or abuse should be a criterion for involvement of an advocate of this nature. If you are

going to spend money, I plead with you to spend it on more medical care and services rather than on advocates and legal hearings.

I also must remark on the provision that, as I read it, entitles an advocate to enter without a warrant any premises where there may be a vulnerable person. Subsection 21(1) of Bill 74 could wreak havoc with families and spouses doing their best to cooperate with an ill family member. The stress level in coping with mental illness is often extremely high. The loss of privacy and of confidentiality implicit in this provision should not be imposed as an additional burden.

The current Mental Health Act has so many individual protections that we have found ourselves at times hoping for a violent act of small dimensions to ensure that our son will be admitted to a safe place, one for example where he will not walk across the street in front of a car because he is watching and listening to his inner world, and where he will receive the needed treatment to help bring him back to his normal, responsible and life-enjoying self.

Through my experiences I have been in contact with a broad array of health professionals: physicians, nurses, orderlies, social workers. I am struck by their common frustration that individual protections have gotten to a point under the current system where health professionals can do little to help. People are passing in and out, recovering slightly so that they are no longer technically incapable and required to follow treatment, leaving in this very fragile and unstable state, discontinuing treatment and regressing to return as though in a revolving door.

Overzealous individual protections can confound the long-term ability of health professionals really to help, and condemn the patient to the consequences of erratic wishes. Let me repeat that. Overzealous individual protections can confound the long-term ability of health professionals really to help, and condemn the patient to the consequences of erratic wishes.

Any legislation must ensure that vulnerable persons are empowered, protected and respected. In achieving these goals, patients must not be denied the benefits of the treatment they need to have a genuine chance of recovery.

Despite the best intentions of the authors, what you have here in Bill 109 and Bill 74 does not work. The goal is right; some of the method is wrong. I recommend that the noted relevant sections of the bills be redrafted. One way to proceed would be to rely more extensively on advance directives and provisions of the Substitute Decisions Act than on casual oral wishes of individuals who may be showing extremely poor judgement, although not technically declared incapable.

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Redefinition of the criteria in principle and in practice for determination of capability might also help. Treatment decisions for those who are not capable should take into account both the views of the patient and his family. In general, family members, not legal representatives, should be the primary group to give consent on behalf of an incapable individual, except where there are clear instances of neglect, abuse or conflict of interest.

More respect should be given to the positive contributions that health service providers can play in informing patients about their rights, and more limits placed on formal hearings and on the role of mandatory neutral advocates. It may also be worth exploring approaches in other jurisdictions to seek better solutions.

I am not sure that my suggestions are the right ones, but I know there are answers and I know that if we put our efforts together we can surely satisfy your concerns and those of patients and their families.

There are real strengths in these bills, lots to build on to meet legitimate concerns. We need more time to restudy options and to find better ways to help patients break out of the vicious cycle of imprisonment in illness and to protect their rights, ways truly "to promote respect for their rights, freedoms, autonomy and dignity," as called for in clause 1(a) of Bill 74, but in this case, of all involved.

The authors have obviously done their very best to protect vulnerable subjects and patients. But how many of them, how many of you, have really experienced the current system and can really imagine what it will be like under the new bills? I have to tell you that I have made an effort to do this in a calm way and that however calm my presentation may have been, there is an emotional storm going on in me. I have tried to do this because of my professionalism and in the hopes that by so doing you will be able to hear me better.

Now I would like to thank you for listening to me in both my hats, that of the national council, in terms of consent for research with vulnerable subjects, and as a mother.

**The Chair:** There are only about two minutes left, so I will allow one brief question from each caucus.

**Mrs Sullivan:** Thank you very much, Ms Miller. Wearing both your hats, you have been able to put forward a highly articulate and highly analytical view that is going to be poignant in terms of the consideration of these bills.

We have asked that the bills be withdrawn to take in many of the considerations you have brought forward and that other groups and organizations, including health care providers and advocacy groups themselves, have put forward. We believe there are fundamental problems with these bills that require a redraft and additional discussion and consultation, with not only the health care providers but with patients and with groups and agencies that support patients who are vulnerable and in those circumstances.

So far the government has refused to do that. We are very disturbed about that because of some of the exact circumstances you have raised. As you indicated, we have had previous testimony regarding the research areas, which my caucus had raised initially in committee when the first briefings were done. We are very concerned about those areas, and I think it was very useful for you to bring the particular issues of research related to children before the committee. So far we have emphasized more of those research concerns in relation to the vulnerable adult, and I think the issues you have brought forward are important. I do not think I have any questions other than to say this has been a very useful presentation.

**Mr J. Wilson:** As Mrs Sullivan has said, we have heard a number of the points before, and both of our caucuses have expressed the desire to see changes in the legislation. We hope the government is listening to that with sincerity.

I do have a quick question, though. You did not touch on the aspect of guardianship in the legislation. I was the only member on second reading in the Legislature to ask that these bills be withdrawn right away, because I was just being flooded as Health critic by not only concerned health care professionals, but by concerned families.

Since that time, though, my colleague Mr Sterling, who is a member of this committee, has managed to convince me that there might be some merit in Bill 109 and Bill 108, and that one of those areas that might have some merit is guardianship. In particular, I have a family member who suffers from schizophrenia, so I know the horror you go through as a family. Have you thought of that area where you might be able to get guardianship over your son? There are a number of groups that just hate the whole concept of guardianship, but in the areas of schizophrenia and manic depression there may be some merit.

**Ms Miller:** I would really have to look at the bills more, and at exactly what they say in that area to know. I guess I live in continual hope that he will be able to take care of himself, and each time we go through a remission period I hesitate even at the notion of seeking guardianship because I try to respect his individual independence, and that would be removal of it. I do think there is something very definitely positive in looking at the Substitute Decisions Act for when he is incompetent. If that is what you are talking about, I think that might be a real strength. But I do not know that I would be able to approach him with that; that would be an insult when he is well and impossible when he is sick.

**Mr J. Wilson:** Yes, it is a very divisive legal channel to have to pursue.

**Ms Miller:** Yes, and certainly it would take an awful lot of sensitivity and care, and I do not know what his reaction would be. I think he would see it as a lack of trust in his ability to take care of himself and to keep on when he is well. So I do not know that I could do that. I think the mechanism is good to have in place and in practice; I do not know if it will work. Does that help?

**Mr Wessenger:** First, with respect to the matter of research, there is no intention to change the existing law on research, and I can assure you that if there is any ambiguity, we intend to remove that ambiguity. Second, with respect to section 16, section 16 would only have a family member involved, because you can only have a guardian appointed or a power of attorney appointed for people over the age of 16. So children under 16 would not come under the Substitute Decisions Act with respect to guardianship or power of attorney. Last, I am going to pass this off to Mr Winninger in respect of pre-validated powers of attorney.

**Ms Miller:** Can I just pick up one of his points for a moment? I have used the example of children, but certainly the arguments apply to other individuals potentially involved in research as well, Alzheimer's patients and so

forth. So I do not think it is as simple as to say it would only apply when they are over 16, because you still have the same problem for research with other populations.

**Mr Wessenger:** Except that the family member would be the person unless the person designates someone to play that role or, second, if the court had appointed a guardian, in which case certainly family members would be the preferential persons for appointing of guardians.

**Ms Miller:** Perhaps I have misunderstood the bill; thank you.

**Mr Wessenger:** Yes.

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**The Chair:** Ms Miller, on behalf of this committee I would like to thank you for taking the time out this morning in coming here and giving us your presentation.

**Mrs Sullivan:** Just on that point, if I could, while the next presenter is coming forward, this is not the first time the confusion about the paramountcy of the substitute decision-maker has come before the committee. If there is that much misunderstanding in the community by people who have examined the bill, God knows how much confusion there would be with people who have not had the opportunities we have had to examine the bill and who are going to have to live with it. Clearly there is an opportunity and an important point to be taken here in terms of redrafting. The bill is not clear.

**Mr Wessenger:** The law is a complex area. In many cases of law we have to have information booklets to explain that.

#### JUSTICE FOR CHILDREN AND YOUTH

**The Chair:** I would like to call forward our next presenters, from Justice for Children and Youth. Good morning. Just a reminder that you will be allowed a half-hour for your presentation; the committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, could you please identify yourselves for the record and then proceed.

**Mr Weagant:** My name is Brian Weagant. I am the executive director of the Canadian Foundation for Children, Youth and the Law. I am accompanied this morning by Cheryl Milne and Sheena Scott, who are also lawyers with the foundation.

If you do not know anything about the foundation, it operates a clinic in Toronto, a legal clinic under the auspices of the Ontario Legal Aid Plan, called Justice for Children and Youth. It is staffed by four lawyers. We practise in the areas of criminal law, mental health law, education law and do work under the Child and Family Services Act. All the representation we provide is for youths who can be instructed, so generally our client group is between 12 and 17 or 18.

The board of directors and the members of the organization are—in addition to lawyers, we draw on most areas of children's services. Not necessarily currently, but in the past few years we have had doctors, psychologists and social workers, all professionals who work with the group that is served by the lawyers in the clinic. The organization

prides itself on being able to promote policy positions that are based directly on the experiences that the lawyers have from practising in the field. I would ask you to keep that in mind when you are looking through our brief. It seems that one of the more valuable things we can do for you is probably to answer concerns, but before we get to that it might be more helpful if Cheryl Milne summarizes our recommendations for you on the bill.

**Ms Milne:** I would like to begin by saying that most of the comments contained in our brief relate specifically to Bill 109. We have not directed any specific comments to the other two pieces of legislation, the Substitute Decisions Act and the Advocacy Act. One of the reasons is that for the most part those two pieces of legislation do not cover the age group we are most concerned with. I think that leads to some confusion in some areas, specifically with the Advocacy Act and what the mechanism is for appointing advocates for the age group of our clients.

The proposed Consent to Treatment Act will have serious implications for all our clients, and especially for those who are living independently. For example, recently Justice for Children and Youth has acted for a pregnant 15-year-old living in secure custody, given advice regarding a 12-year-old girl who thought she was pregnant and assisted a 15-year-old in need of dental work after her parents had kicked her out of their home. Another 15-year-old client of Justice for Children and Youth sought medical treatment for bruises and swelling caused by an assault on her by her mother. As she was about to turn 16 and was living with friends, and therefore was out of immediate danger, the child welfare authorities refused to get involved. All these clients would be adversely affected by the legislation proposed under Bill 109.

What I am going to do is just summarize some of the points in our brief. The last two pages of the brief set out a summary of our recommendations. You can either follow that or try to follow me as I go through the brief.

The current situation is one in which the common law applies to our clients, and the common law generally has acknowledged that minors gradually acquire rights as they grow older and become capable of discernment. The few cases decided in Canada on the issue of consent to medical treatment have clearly held that a minor may consent to medical treatment if he or she has sufficient intelligence to understand the particular treatment in question.

The fact that a patient is a minor should possibly alert the physician to clearly scrutinize his or her intelligence and maturity, but should not act as a bar to independent decision-making. Unfortunately few health care professionals know the common law, in our experience, and many deny services to young people on the assumption that the law is more rigid than it is. There are also, unfortunately, those who make such decisions based on who is more likely to sue them than on who they are facing in terms of who the patient is.

The current situation can lead to uncertainty in the treatment of youth. For example, a 13-year-old in secure custody under the Young Offenders Act is deemed to have the capacity to consent to treatment provided in that facility. However, the same person would not have that power

if he or she were within a secure treatment facility under the Mental Health Act. Similarly a person under 16 can consent to certain surgical procedures if performed in a doctor's office or medical clinic, but would not have the ability to consent to the same procedures if conducted in a public hospital.

Another example is the difficulties high school students have in obtaining counselling from school social workers because school board policies often require prior parental consent. This consent is not required for counselling by social workers under the Child and Family Services Act or at common law.

The present situation is really not satisfactory. However, the legislation provides specific age limits in an effort to make things more certain. It is our position that in fact it makes things worse for our clients. The danger in using arbitrary ages and a negative presumption below those ages is that health practitioners may use them as rigid cutoff points without properly determining the young person's actual capacity. There seems to be no logical basis for presuming that a young person under 16 does not have the intellectual capacity to give informed consent. The studies demonstrate the contrary. A health professional should approach minors with no presumptions whatsoever, and only in this way will health care providers be sure of taking the additional step of inquiry into the actual capacity of the young people seeking assistance.

We submit that the common law position is preferable to fixing the age of consent at some arbitrary age with a rebuttable presumption below it. Artificially fixing an age of consent or an age of presumption fixes too rigid a cutoff point for access to health care. To point out that different children mature at different rates is stating the obvious. It is because of the great variety in the rate of development of human intellectual and personal maturity that we feel it is important that the common law rule of informed consent should be maintained and clarified, regardless of age.

Setting that aside, however, we must acknowledge that under the present system many health practitioners are denying treatment to young persons without parental consent because of a lack of knowledge about the common law rules. This situation has been documented in studies involving doctors in the Toronto area.

Denial of services to young people as a result of consent requirements may be avoided by specifying the new age limit as 12 rather than 16. So our first recommendation is that a person who is 12 years of age or more should be presumed to be capable with respect to the treatment, but that presumption may be rebutted.

Our second recommendation deals with the issue of confidentiality. By setting the age at 12, we are not suggesting adolescents should make these decisions on their own without adult consultation. However, this should not be a condition of obtaining treatment where the young person is clearly capable of making a decision. Should the young person decide not to tell his or her parent, the discussions with the health practitioner should be protected as confidential communications subject only to the duty of health practitioners under specific legislation to report suspected child abuse. That is the Child and Family Services Act.

Our second recommendation deals specifically with clarifying that point so that, regardless of whether the person under 16 chooses to involve his or her parent, and even if the health practitioner determines that the person does not have the capacity to consent to treatment, patient confidentiality should be maintained subject only to the obligations imposed by law.

Another issue that comes under the legislation is the definition of "health practitioner" and "treatment." Under the proposed legislation, "health practitioner" is defined as those professionals listed in the appendix to the act. The list, in one sense, could be seen as being too broad and somewhat illogical and in another sense too narrow.

1030

It is our view that if you assume the age for presumed capacity to consent is 12, then definition of "health practitioner" should be broad so that therapists and social workers in a variety of settings are covered within the legislation. It should also be clear that services which are purely educational in nature should be specifically excluded under any broad definition of "treatment."

I am going to skip through some of our recommendations. I think you can follow through them. I am not going to point to all of them specifically.

Another issue that I think is linked to the confidentiality issue, but also to the ability for the young person to go to more than one health practitioner for an opinion, is that the legislation is unclear as to whether a person can merely seek another opinion upon learning that his or her practitioner has decided that he or she is incapable. It is our position that the act should provide that the minor be informed that one refusal to treat does not constitute an absolute ban to treatment should the minor be unwilling or unable to seek parental consent. This may assist a young person who has been refused treatment by a health care provider who is also loath to treat any particular minor or who considers all minors incapable of giving informed consent. That has certainly been part of our experience, that there are some health practitioners out there who will not treat young people for various reasons.

It is hoped that a conscientious health professional will explain the refusal, but should he or she fail to do so, the statute would require that the grounds for the refusal to treat be provided. If the minor feels strongly that he or she has the requisite capacity to give valid consent, the young person should be able to seek a second opinion elsewhere.

Another issue is who will consent. Consent to treatment on behalf of a young person under 16 or any person found not to be capable by the health practitioner can be made by that person's parent or other relative, as long as that person has had contact with him or her within the last 12 months. The time period allotted appears much too long. Many of our clients who are living independently of their parents may have ceased contact a relatively short time previous to the need for treatment. However, the contact they have had with their parents may have been highly conflictual. For example, a pregnant teenager recently forced to live independently of her father was told by him that he wanted contact with her only because he wanted contact with the grandchild. He had thrown her out of the

house. Should this man be given the power to consent to treatment on behalf of his daughter through her pregnancy?

Recommendation 10 is that the relative empowered to give substitute consent on behalf of a person should have had contact with that person, we say, within the last three months, and there should be a mechanism within which the Consent and Capacity Review Board can review the nature of the contact between the parties so that if it is characterized by conflict, that can be taken into consideration when looking at their decision.

Respecting the review board composition, the members of the Consent and Capacity Review Board are to be appointed by the Lieutenant Governor in Council. There are no guidelines, except as to numbers, in the requirement that one person have expertise in determining capacity for the composition of the board. In contrast, the Mental Health Act will continue to specify that the board appointed pursuant to that legislation will be composed of a lawyer, psychiatrist and layperson.

Given that the capacity to consent relates to a specific treatment, at least one member of the board should have expertise in such treatment. Furthermore, there should be diversity among the members of the board so that it is not composed of, for example, all doctors. Finally, and most important, if the review board is to determine the capacity of a child or adolescent, the board should consist of members who have experience with that age group.

The implications of this legislation are also that there are going to have to be other amendments to the Child and Family Services Act to keep it in line. If our position with respect to age applies, then I think the regulations under the Public Hospitals Act also have to be looked at, where 16 is an age with respect to surgical treatment. If your intention is to try to organize things in a way so that doctors know exactly where they stand, I think all these other pieces of legislation have to be looked at, because right now with young people under 18 there are different rules for different ages and different types of treatment and it is quite a maze. We would recommend that those other pieces of legislation also be specifically looked at.

I have gone fairly quickly through the brief and just sort of pointed out the highlights. Our main issue, I have to say, is probably the age issue and the fact that the common-law position where the doctor looks at the patient, or the health practitioner looks at the person in front of him as an individual is the preferable route. But if you are going to set up a system of presumptions, we think that 12 is an age you can actually justify. It is an age that is established under the Young Offenders Act for someone who has the power to instruct a counsel. There certainly is a lot to support 12 as an age for a presumption, so there would be a positive presumption in favour of capacity above that age.

I think it also helps doctors or other health practitioners in giving them some certainty as to how to deal with someone who is 15 and standing in front of them, rather than have a situation where it is left open with just the common law. There certainly have been a lot of problems with this age group in terms of health practitioners refusing to provide them with treatment because of uncertainty

as to how they should deal with them and what the parent's role is in the whole situation.

Sheena Scott is going to talk about some of the proposed changes that have been put forth by the Conservatives to the bill and what our opinions are in respect to those specific changes.

**Ms Scott:** Before I get into that, I want to talk a bit about rights advice under the legislation. Under the proposed legislation, if you are 16 or over you automatically get advised of your rights but if you are under 16 you have to assert the desire to make your own decision before you are told the presumption is rebuttable. This is clearly unfair. How we can expect a 12-year-old going into the doctor's office to know the mechanism of the legislation and to have basically the guts to say to the doctor, "Hey, wait a minute; I really feel I'm competent and I can make this decision to have my acne treated," it seems to me is one of the flaws in terms of making an age of distinction. Even if we do reduce the age to 12, we would suggest that all people must automatically get rights advice and that it should not be left up to the child to make an assertion that he wants to make the decision himself. It just will not happen.

Also, the other point I wanted to address was with respect to clause 17(b) of the act, which states that if a parent is going to be making a decision on behalf of a child, he or she must indicate that he or she has no reason to believe the incapable person might object to him or her making the decision to give or refuse consent. With most of our clients there has been some kind of conflict with the parent: sexual abuse, physical abuse, dispute over the rules of the household, that type of thing. Often, particularly in the sexual abuse cases, the perpetrator is denying the abuse, so he might, in good conscience, or in his own good conscience, make that statement under clause 17(b): "I don't know why they wouldn't want me to consent to this abortion, because there's nothing wrong. I didn't do anything." Would the health practitioner be bound to accept that consent in those circumstances? Hopefully not, but there is no mechanism to look into the conflict or the relationship between the parties, and I think that highlights one of the recommendations Cheryl mentioned.

We have before us some amendments proposed by the Conservatives. One was that the definition of "treatment" be somewhat narrowed to exclude prescribed things or the provision of information. We agree with this amendment. We think it would be very difficult and impractical for the person behind the counter at the drugstore to have to make a determination of someone's capacity if someone goes and hands him a prescription. We hope this amendment is designed to deal with that by excluding prescribed things from the definition of "treatment." Also, with respect to the provision of information, clearly public health nurses and other professionals who go around to schools and speak should not have to assess the capacity of every individual in the class to provide them with information. We feel this narrowing of the definition would be beneficial.

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The one thing we do have concerns with about the overall definition in the legislation is the word "cosmetic." Is getting your ear pierced cosmetic? That is unclear. For that reason we do agree with the Conservatives' other recommendation that the Lieutenant Governor have regulation-making power in terms of what does not constitute treatment.

Finally, the Conservatives have also recommended that section 8 of the bill be struck out and the following substituted, "A person is presumed to be capable to consent to treatment if he or she is capable of understanding the nature, purpose and consequences of the treatment." This is essentially the common law. Cheryl has already addressed our views on the common law and that in the ideal world it would be the preferred solution, but unfortunately these decisions become very subjective and discretionary under the common law.

The other problem with it is that the Conservatives have made no mention of when the rights advice will kick in if their recommendations are implemented. Does this mean only those 16 and over get rights advice? That is an anomaly that will have to be addressed.

**Mrs Sullivan:** You have raised a lot of issues relating to the age provisions and the Minister of Health, in her first presentation, indicated to the committee that there would be changes. Certainly we have much concern about the mature minor who has the capacity to consent to certain treatments, and I think now there is all-party agreement that there should be changes. We had hoped there would be amendments brought forward during the course of this discussion so that people would be able to look at them and so that we would indeed be having public consultation based on what in fact the government will really be considering.

You raise issues in relationship to the Child and Family Services Act and other issues, the blanket authorities to CASSs. The question that comes up is collecting of evidence for incest victims. Those are questions where far greater discussion over the course of this age issue is going to have to come into play. We do not really have an awful lot of time to go into those things now, but we have asked, through the parliamentary assistant to the Minister of Health, for additional work to be presented to the committee in relationship to some of the consent issues for wards and so on. We hope that will come forward and that many of the issues you have raised in terms of age will be dealt with in an appropriate way, and also that there will be additional public consultation in relationship to what the final amendments and final proposals from government are. So far that has been refused, but we will keep fighting.

**Mr Sterling:** Thank you very much for your support for our amendments. Early on in these hearings, as soon as we had heard three or four groups, we thought a more logical way to approach this would be to advise subsequent groups that we had made a determination that there was a problem. Let's work together to fix it and not have everybody lashing out at provisions where there was already a sort of consensus that there was a major problem. With

regard to the interesting question you raise, at what age an individual is entitled to advocate services, are you suggesting that while the common-law definition is good, there should be a cutoff age when a child is not entitled to advocate services?

**Mr Weagant:** We understand the problems with drafting legislation in order to cut out some people but not others. In an ideal world we would say there should be no need for legislation and that all decisions around consent should be made by a determination of competency. We know the world does not work that way and that most decisions about competency are truly motivated by who is in a better position to sue and whether the patient agrees with the treatment being offered. That is our experience. That being the case, there has to be some compromise position if you are going to try to codify it.

At this point in time, given that the proposal is 16, we think the most progressive way to satisfy our concerns and the government's concerns would be to cut it off at 12. We do not think we are tossing away that many competent people under that age who would need a triggering mechanism. If indeed those kids exist, they can come for our services. In the last few years we represented two kids who, at 11 and 13, were at Queen's University. Surely for their problems, when they came up, we could have taken them forward. We are suggesting that a safe cutoff, if you have to have one in order to ensure integrity in the system, may be 12 for the triggering mechanism. It does not mean persons under that age should not be entitled to seek help on the question or that they could prove capacity if need be.

**Mr Sterling:** Okay. This question has been posed to us: An eight-year-old walks in to the dentist's with his mother and the eight-year-old says, "No way I'm climbing into the chair." The mother says, "Johnny, you're getting in that chair." What happens then? He is clearly saying no. What are you suggesting? Are you suggesting he should have a right of access to an advocate, or do you think there should be some age where the parents are deemed to be the advocate for the child?

**Mr Weagant:** As a practical matter, what happens now?

**Mr Sterling:** He gets in the chair.

**Mr Weagant:** You do not think that is going to continue?

**Mr J. Wilson:** All the dentists tell us it may not.

**Mr Sterling:** Yes.

**Mr Weagant:** It seems to me to be a bit of guerrilla warfare when they are giving you submissions. Are they saying as a group they will now, after all these years of deciding that kid was incompetent, decide that kid is now suddenly competent and that is why this legislation should fail? I find that hard to believe as a practical matter, that this is how the world is going to work after this comes in.

**Mr Sterling:** No, but we are dealing with legislation, with legal rights, with liability issues etc.

**Mr Weagant:** Yes, lawsuits, insurance.

**Ms Scott:** Whether or not he gets into the chair is not the issue. The issue is, is he competent to make that decision whether or not he gets into the chair? The dentist still has the power to make that determination, and if he feels the child is not competent, based on the child's age and intelligence and whatever test may be prescribed under the legislation, then he has the right to make that determination that the child is not competent to make that decision and to rely on the parents' decision. The question of whether or not he gets into the chair is a red herring.

**Mr Sterling:** No. If the child is not competent, then he has to call in the advocate, according to the legislation.

**Ms Milne:** An example of how that is actually coming into practice at present is with the Hospital for Sick Children, where kids are brought in with respect to mental health care. Even though they are not legally bound to provide these children with legal advice, as a practical matter they let them know they have the right to a lawyer. They are being brought in by their parents, probably through some coercion, but they are there and they are given the advice. Very rarely do they actually take that opportunity to obtain a lawyer and fight it. We have had three calls in the last 10 months.

**Mr Sterling:** Yes, but you are mixing apples and oranges here. You are confusing the issue with a very serious health problem when you are dealing with what we would describe as a maintenance health problem.

1050

**Mr Wessinger:** There are just a couple of points I would like to raise. First of all with respect to the matter of age, you indicate in your presentation that your preference is for no age and for having the common law, and then your recommendation is setting the age. I should tell you before you answer this that generally the advice we have been receiving from health practitioners and people in the field is that they prefer the common-law approach. If you had your choice, would you prefer the common-law approach with health practitioners, assuming there is an educational process, or do you prefer age 12?

**Ms Milne:** The ideal situation, the perfect world situation, is where we have the common law, so that each health practitioner approaches each person as an individual and makes the assessment as to whether or not he has capacity, based on the rules.

However, it has been our experience that when a health practitioner is faced with an adolescent the rules change. It is very difficult for that young person, despite how mature he or she may be and the fact that he or she can understand the procedure, especially when it gets into sensitive areas such as abortion and pregnancy and those areas. We have certainly had the experience where doctors have said to our clients: "I have to call your parents. You're only 15." It is clearly not true, but that is what has been happening. Therefore, we have said that if you at least put a presumption at a certain age, there is some certainty, so you are more likely to have a health practitioner treat that adolescent based on the presumption.

I do not think we are going to get that ideal world. People have been talking about the problem about the lack

of knowledge health practitioners have about how to test capacity for this adolescent group. We did a brief in 1980 on the same issue, and it is still happening. We are not that confident that the education process is going to suddenly, miraculously change things for our clients, so we are willing to put a cutoff point for a presumption. It means that the test still has to apply, and that presumption could be rebutted by the health practitioner who is faced with a 12-year-old who he does not think really understands the nature of the treatment.

**Mr Wessenger:** My second question is with respect to your recommendation with respect to social workers and therapists. I was wondering why you would really want them included under this situation, because what they would be doing generally would not be a treatment at all. That is why I was curious what the advantage of including them would be.

**Ms Milne:** Why would you include psychologists and not other forms of therapists? You either go broad and allow more people to be included under the act or you narrow it down. Right now there does not seem to be much rhyme or reason to the definition of "health practitioner." You cover some people who provide therapy and some who do not. Right now we still have the same problem where social workers are saying: "I have to call your parent, because we're not necessarily under the CFSA. We are within the school board, so we can't even counsel you as a school guidance counsellor without calling your parent."

**Mr Wessenger:** I just do not understand on what legal basis they do that, because it would seem the common law would apply to them as well, unless there is any legislative, and I am not aware of any legislative—

**Ms Milne:** That is what we would say, but I think that to provide more certainty to that group, they should be included as well.

**Mr Wessenger:** So really you are just concerned about people not following the common law again in this instance?

**Ms Milne:** I think that has been one of our biggest issues.

**Mr Wessenger:** I have one more question I would like to ask.

**The Chair:** Thank you, Mr Wessenger. That is it.

**Mr Wessenger:** No, I think this is an important question.

**The Chair:** No. Thank you, Mr Wessenger. Mr Weagant, Ms Milne and Ms Scott, on behalf of this committee I would like to thank you for taking the time out this morning and coming here and giving your presentation.

#### PATIENTS' RIGHTS ASSOCIATION.

**The Chair:** I would like to call forward our next presenters, from the Patients' Rights Association. Good morning. I just remind you that you will be given a half-hour for your presentation.

**Mrs Coy:** We have made it brief.

**The Chair:** The committee would appreciate it if you would keep your remarks to about 15 minutes to allow

time for questions and comments from each of the caucuses.

**Mrs Coy:** Very good.

**The Chair:** As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Mrs Coy:** My name is Anne Coy. I am the president and co-founder of the Patients' Rights Association. Why did I get involved in this, I keep asking myself. Simply because, as we say in our presentation, if you have been there, you can talk about it.

My husband was a victim of an improperly prescribed medication, and I did not even know where to go with a complaint about that. A neighbour said, "Why don't you go to the College of Physicians and Surgeons?" I did not know what CPSO was. So we feel strongly that there has to be something in the legislation that is going to educate the public about how to handle things.

You will notice in our presentation, which I do not intend to read to you, that we are concentrating on two aspects of our work. One is advocacy, with which we have a considerable amount of experience, and Harry will speak to you about consent. If, at the time we as a family were in trouble, there had been an advocate about who could have explained to me that it was all right to ask questions and to criticize treatment, my husband might still be alive and I would not be here. But I thought since nothing was going to be done to prevent the avoidable medical accident from happening to someone else, if we are not going to be protected as the public and as patients—and we are all potential patients—by the regulatory bodies, therefore we have to do something to protect ourselves.

I was surprised to find, when I was involved with the government's review of the Public Hospitals Act, that we had to fight hard to establish the fact that a patient is a stakeholder in the health care system. You would be surprised at the amount of time we had to take to talk about the role of an advocate, because it is seen as adversarial, and it certainly should not be. This is why we concentrate on the importance of the Advocacy Act.

Get rid of the idea we are there to fight the system. We are there to help to accomplish the highest possible level of health care. We were naïve enough to assume we all had the same goal, providers and patients alike. I asked the committee during the review of the Public Hospitals Act if they were against the concept of advocacy or the word "advocacy." I do not know what you can substitute for "advocate." I know in the legal sense it is an adversarial system, but not in the sense of speaking for someone who is vulnerable, and we are all vulnerable if we are ill. We are intimidated by illness and we can be intimidated by the system. So this comes as a very pleasant surprise to us. As it tells you in here, I was on Father Sean O'Sullivan's consumer advisory committee and felt pleased to be asked to give an opinion as a user of the system. We were quite pleased to see his act go in and we are hoping it is going to go ahead.

The idea of advocacy, even though we have been volunteering for 18 years, is really too important to be left completely to volunteers. The majority of people do not

know that we are around or that we are available. Maybe that is good, because we would not be able to handle the workload if they did. We have reached the point now where we are not seen as enemies or in opposition to the giving of health care. This is witnessed by the fact that we are able to come and speak to a committee such as this, or that we would be asked to take part in a review of the Public Hospitals Act, or that we would be asked to do many of the things we have done.

We have outlined here, for those of you who do not know about us, what our goals are and how we are going about trying to accomplish those goals. We point out to you the amount of work we have done voluntarily since 1974. We have had a physician on our board. We have a lawyer on our board. We have a nurse on our board. So we have input from the providers of care.

On page 2 of our submission, towards the bottom, we point out how important it is to ensure consumer control of the direction of the advocacy system. Once you have been in this position you know how important it is to have someone who at least can promote self-advocacy, even give you the assurance that you are entitled to speak for yourself, which is the best kind of advocacy, if the person can do that. In our society we have so many citizens who do not have English as their first language and they cannot put their complaint on paper. There are a lot of people who have English as a first language who cannot do that. They could tell you what the problem is. In discussing the problem, they may find there really is not one, once someone takes the time to explain it to them. That is a function of an advocate, too, I would think, to clarify a situation.

1100

We do a lot of just talking to people. The majority of our cases now are dealt with by the complainant himself or herself. We got involved actively at first by taking part because we were not sure ourselves what the system was. We have appeared before the Health Disciplines Board and we have written letters for people. Now we advise people how they could write their own letter. If we find that it would be an impossible chore for them to do so—you know, let's not write 20 pages and still not say what the problem is. Let's not use certain words like "murder" and what have you. If we find they cannot do it themselves we would draft a letter, either for their signature or actually write it on our letterhead, as a third party who is intervening.

We point out on page 3 the factors, or the qualifications perhaps, an advocate should have. An advocate must be free to use judgement. Therefore, it should be known that this person is capable of using good judgement, because you are advising someone else. We are not for the best interests approach: "I know what is best for you. This is what you should do." We find out what the person wants to accomplish, how he requires the help to accomplish this, and we see this happening if the Advocacy Act gets in place. I understand there is a lot of resistance to it, but it is improving. I did not think it was going to take 18 years to get to the point where I can say we are not enemies of the people.

There also has to be the ability to communicate and to understand communication, because you have to be able to

assess whether the person you are advising is capable of understanding your advice, the system and what you are saying, and whether he is able to proceed on his own. You have to avoid at all costs telling the person what to do. The person tells you what he would like you to do. We cannot take away the independence of the individual. We sort of encourage independence. It is surprising how courageous people will become if they know they are not on thin ice, "Are we allowed to question what is happening, what is being proposed?" Very important decisions have to be made involving life and death in the health care system and I guess none of us can avoid being vulnerable at some time or another.

Perhaps we can pass it over to Harry now to talk about our views on consent.

**Mr Beatty:** I am going to address particularly—it begins on page 4 of our brief—sections 4 and 5 of Bill 109, which set out the general law of consent.

Most of the bill and most of the public debate has centred on incapacity. We thought we would focus a little bit on the general law of consent and the status of actual practises around consent where there is no issue of incapacity, where the patient is a competent adult and that is not being questioned. Even in those circumstances, the practices as to consent in Ontario's health care system fall far short of what is theoretically the legal standard, as set out in subsection 5(1) of the bill that, "The consent must relate to the particular treatment, ...must be informed and ...must be given voluntarily."

Many examples have come to our association's attention. When I say "our association," it is really to Anne Coy's attention, because although Anne has been a volunteer all these years, she has put in a workload, as many volunteers do, far beyond what paid employees do. Anne has talked to literally hundreds, perhaps thousands, of consumers in Ontario's health care system over almost two decades.

Some of the things people tell us are just common experiences you would be aware of. Some people are asked to sign general consent forms on admission to hospital before they know what their diagnosis is, or what treatment is proposed. They are just very general blanket consent forms. In law, they are not consents to anything. That consents are obtained in this manner really gives people the impression that consent is much different than it really is. While consent forms are supposed to be signed voluntarily, we have had examples reported to us of consent forms being presented to patients under sedation, sometimes in the operating room itself.

If people want to make changes, like a few examples of people who had some problems with being involved in teaching in teaching hospitals, clearly changes are not regarded as acceptable. Anne has dealt with some cases where parents—I think the cases dealt with have been mothers—have been told that they will be reported to the children's aid society if they do not consent to treatment for themselves.

**Mrs Coy:** One was for herself, the other was for her child.

**Mr Beatty:** There is usually nothing about the risks of the proposed treatment or procedure, although some hospitals, with regard to specific procedures, have done a very good job of developing information sheets, but often people know next to nothing about the risks, and of course it is very unusual for people even to be given a copy of the consent form they have signed.

Drugs with significant risks are often prescribed on the basis of an implied consent. There is really no full explanation of what to look for in terms of risks or what to watch out for in terms of side-effects. There are also concerns about delegation where consent is obtained by someone other than the person who is actually providing the treatment.

Our recommendations concerning sections 4 and 5 are that while "informed" is defined or explained, there is no definition of "voluntariness." We believe there should be one, to make it clear that any kind of duress invalidates the consent. Subsection 5(3) just says, "Consent to treatment may be express or implied." We believe there should be, perhaps by regulation, a requirement that for certain classes of procedures there must be a written consent. We also recommend standardized consent forms or, failing that, at least some legislated guidelines as to what can or cannot be on a consent form.

1110

A few years ago we reviewed some consent forms that people sent us from various Ontario hospitals and found all sorts of provisions that were very questionable in terms of the law, the chief one maybe being the generality in some of the consents. There should be an onus on health care practitioners to prove they have obtained a voluntary informed consent if an issue arises.

Finally, as we have said many times over the years, we believe consumer complaints in the health care field should be heard by an independent, impartial body rather than the self-regulating professions.

A system based on truly voluntary and informed consent is clearly much different than the system we have now, where consent is not taken all that seriously. I think we have to recognize that we are not going to have the system envisaged by these bills operating effectively overnight. It is very different. It is going to require a great deal of education of both providers and consumers.

The position of our association, like that of other organizations in the Ontario Advocacy Coalition, is that the advocacy system has to be in place before you bring in the other bills, or at least before you make the other bills fully operational. Even then a lot of work has to be done on finding some way to phase in these new legislative systems.

In an ideal world, people who are not capable of making their own decisions should have a substitute decision-maker identified. Those of us not currently considered incapable should have personal powers of attorney so that it is clear where people should go in the event that we are in an accident or something of this kind. In practice, that has not happened yet, and to move towards that kind of system, a more rational system that makes sense, is going to take a good number of years.

Without going into the specifics, we would support reasonable compromises to target advocacy resources at those most in need during the first years of the new legislation. It has been about 25 years, I think, since the first guardianship committees were appointed by the provincial government to revise the Mental Incompetency Act, so this has been a very long debate. I served on the first committee, chaired by Steve Fram, and for some time on the second—I think we were appointed in 1983—and these issues were certainly part of deliberations about these issues before that time. So the issues are not easy, and a lot of this will take some getting used to, but I think consideration has to be given to finding ways to phase this in.

Without giving an exhaustive list of the criteria, they should take account of the seriousness of the procedure and whether there are special considerations that make a person vulnerable. If the system were just sort of implemented in full on January 1 of some year, it would basically require that advocates get in touch with every vulnerable person in the province pretty well during the first number of months, and clearly that is not possible.

But in principle, while some amendments should be made, the association supports these bills as the direction that should be taken in this area over the next number of years.

**The Chair:** Thank you. We have time for one brief question or comment from each caucus.

**Mrs Sullivan:** I think it is a shame we have so little time, because we have a lot of respect for the work that groups such as your own do. I think in terms of my question, I would like to go to Mrs Coy, who was a member of the O'Sullivan committee. I am going to ask, given the report of that committee, if you were surprised that the legislation did not include some of the proposals included in that report about the duty to report abuse and neglect, such as the examples that were given from the jurisdictions of Minnesota and Nova Scotia. We have had other testimony that indicated that might be an appropriate way to go, and exists in children's services. I just wondered if you were surprised that was left out.

**Mrs Coy:** No, I was not. I was disappointed at the time that consideration was not given to those of us who become temporarily vulnerable. He did not deal with children, with the vulnerability of the child; his mandate did not include that. I was not surprised. The duty to report—

**Mrs Sullivan:** The duty of care givers to report abuse in a situation: That was one of the things included in the O'Sullivan report that is not included in the legislative proposals that deal with vulnerable people in society. It seems to me that is a very simple and useful change that could have occurred.

**Mrs Coy:** I think that was discussed by several groups in the proposals that came out of the Health Professions Legislation Review, that there should be a duty to report, on the part of the provider of care, any abusive situations or any harm that was being done even in the provision of care. I realize that is being objected to quite strongly. I think Dr Boadway from the Ontario Medical Association

calls it the snitch law. We do not always consider a duty to report as snitching, I do not think.

**Mr J. Wilson:** Thank you for your presentation. Just very briefly, in your written text you talk about accountability for health care practitioners. What about accountability for advocates? As I read the acts, there is not much, if anything, in there.

**Mrs Coy:** I think the advocate basically must be accountable to the person being represented. We call them clients, which is not a very good word. There must be accountability, of course, because you realize when people come to you with a problem, you can be held responsible if things go wrong as a result of someone taking your advice. So it definitely has to be there. I guess we mention that an advocate must indeed be capable of showing good judgement.

**Mr Beatty:** I would also strongly support accountability for advocates. If an advocate goes off the rails, it can become part of the problem for an individual. There is nothing to guarantee that advocates are going to be perfect, and advocacy programs and so on should have a complaints procedure available and all the other kinds of consumer remedies just like every other kind of program.

**Mrs Carter:** I would like to thank you for your understanding and support of what we are trying to do in Bill 74. I believe it is set up to maximize consumer control, so I think we are with you on that point, but there are two questions I would like to ask you.

On page 3 of your presentation you raise the question of non-directed advocacy. As far as the act goes now, the advocate is confined to ascertaining the wishes of the vulnerable person and acting on those, so if the person cannot express any wishes, then presumably the advocate is powerless. We have the situation where a person is obviously being abused but cannot express any wishes. I wonder how you would like to see reactions to that kind of situation being incorporated into the act.

I would also like to know what you feel an advocate should do in a situation where a person who is capable of expressing wishes is saying the abuse he may be subjected to, or neglect or whatever, should go unreported. What should the advocate do in that situation?

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**Mrs Coy:** I did not hear the end of that question.

**Ms Carter:** If a person is capable but requests the advocate not to report abuse or neglect or other problems, what should the advocate do in that situation?

**Mrs Coy:** If the advocate is going to be taking direction from the individual, and we are talking now about the user of the system rather than the provider of care, he or she cannot overrule—otherwise, you would not be speaking for that person if you imposed your own ideas.

**Mr Carter:** Right.

**Mrs Coy:** In the 18 years that I have been doing this on a voluntary basis I have had to learn from scratch how to do it, but I knew what I would have liked when I needed help. I have not come upon the things you suggest. Most people who come to us do not come in the spirit of re-

venge. They had the same feeling I had: Can we keep this accident from happening to someone else? It is quite altruistic, I think, that they take the trouble to go through the process, because it is a harassing process. If there are pitfalls in what they want to do, then I think it is up to the advocate to point that out.

One man was complaining about the care provided to his wife, who had died. It was the only case, really, that I had to turn down in all those years, and I did not exactly turn it down. He was in a place outside Toronto. In Toronto, if you do not like this doctor, you go next door and there is another one. He had a chronic heart condition, and I said, "Who is your doctor?" He said, "The same person." I said, "Are you thinking of changing doctors?" He said no, he was satisfied with this doctor. I said, "What do you think his reaction will be if you put in a complaint about him? Do you think you might find yourself in a position where he will say to you, 'I do not want you as a patient any longer?' which is within his rights?" He had not seen that as a possibility, but he did not care.

**The Chair:** Ms Coy, Mr Beatty, on behalf of this committee, I would like to thank you for taking the time out this morning and giving us your presentation.

#### CASEY HOUSE HOSPICE

**The Chair:** I would like to call forward our next presenters, from Casey House. I just remind you that you will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Mr Graydon:** My name is Douglas Graydon. I am the coordinator of counselling services from Casey House. Frank Foley and Deborah Randall-Wood could not attend. They had planned to do that. I will be very brief.

Based on Casey House's limited experience of four years, we would like to share some concerns about the legislation we are discussing. As outlined in the papers that have been circulated, we begin with Bill 108 around definitions of terms and the definition of the term "partner."

Our concern, based on our experience, is that if the validity of a partner relationship is dependent upon the recognition of others as to the primary importance of the relationship, then the potential for true conflict really does arise. Casey House believes that a partner relationship in terms of a same-sex relationship, for example, should be determined by the partners involved and not be dependent upon external recognition by others.

Also in that same bill, we have concern around the issues of research and how this legislation may limit AIDS research opportunities. One of the peculiarities of AIDS is that a person's capacity can fluctuate significantly from day to day. A person can be deemed capable of making decisions one day, and several hours later, not. So we are wondering if some thought can be given to an appropriate mechanism, which while safeguarding a patient's rights and dignities, would allow for research in the relatively new field of AIDS.

Under Bill 109, the Consent to Treatment Act, comments worth noting are the definition of the word "treatment" and exactly what is meant by that. I believe you have been presented with this concern before, whether or not treatment includes investigation for treatment. If it precludes the opportunity to investigate until capacity to consent is determined, then significant limitations are placed upon a health practitioner in the case of an emergency. I am not talking necessarily about a critical emergency, but possibly one that can take place within 10 to 12 hours. I believe there are areas of the legislation that try to address that.

Section 8, presumption of capacity: I believe you had a presentation just a short while ago about the problems and concerns around the age limitation of 16, especially for young adults under the age of 16.

Section 9, definition of "prescribed criteria" and/or "procedures": Our feeling or our concern is that this statement does not clearly define what is meant by prescribed criteria or procedure, who or what body determines criteria or procedures and under what jurisdictional body this responsibility lies. There can be differences of opinion as to what is an acceptable procedure based on an institution's history and experience, so there can be differences from one place to another.

Finally, comments on Bill 74, the Advocacy Act: Clause 1(e), under the purposes of the act, makes reference to native or aboriginal Canadians as a specifically distinct group. We question whether there should be some reference to broadening that to include groups such as gay and lesbian groups or to incorporate some form of mechanism that allows specific communities to lobby for a designated status.

Under subsection 16(1), rights of entry for the advocate, our concern is that the right of entry should include, whenever possible, the consent of the vulnerable person whom the advocate is seeking to assist. If the vulnerable person does not want to see an advocate, does the vulnerable person have the right to refuse the advocate's entrance?

The final comment is on clause 24(3)(a), the advocate's access to records: The way we read it and understand it now, we wonder whether the physician's consent should be changed to the physician's knowledge. In this rewording, we believe it might preserve the vulnerable person's right to access to his own medical information. It also eliminates the possibility where the advocate could be denied access to the vulnerable person's medical information.

Those are the comments and concerns we have. Thank you for your time.

**Mrs Sullivan:** Before I start the questions, I want to tell you how much I admire the work of Casey House. I have had friends who have used the services there, and the care and treatment they have obtained at Casey House has been quite extraordinary and loving. I just wanted to say that.

In asking questions about your presentation today, I particularly wanted to have you expand on concerns relating to advocates' access to records. We are all concerned, and there have been issues relating to confidentiality surrounding HIV patients. In the case of Bill 74, the advocate

does have access to patient records, and certain limitations on disclosure other than in certain circumstances. I wonder if you believe that the circumstances included in the act for disclosure of patient records without the patient's explicit permission are appropriate, and indeed how that would affect the patients with whom Casey House particularly works.

**Mr Graydon:** I have to begin by saying that I am not that familiar with Bill 74. Deborah Randall-Wood was the one who did the research on that, so I really cannot say with absolute certainty whether the safeguards incorporated in that bill are sufficient.

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**Mrs Sullivan:** I am concerned that the advocate, in section 30, has the ability to disclose, without consent, information about a vulnerable person obtained from the clinical record to other people who work for the commission and to other people who work in a community program, and to any other person with the vulnerable person's consent. There are two subsections of that section where the vulnerable person's consent is not required.

**Mr Graydon:** I can only say that from our experience, I would assume that the advocate, in disclosing information, would be disclosing it to people who understand the need for confidentiality. However, that being said, we still continue to experience the situation where harm is done to the person when his HIV status is disclosed. So my assumption would be that Casey House would be deeply concerned that this type of information would be shared unnecessarily, and that there must be some kind of safeguard specific to, possibly, HIV-positive standing or status. We have experienced situations where people have shared that information with the assumption it was confidential, and it has not been kept confidential by professionals, and harm has been done to the vulnerable person.

**Mrs Sullivan:** I wonder if Casey House would look in particular at that section and perhaps submit another brief. I think it would be useful. I am quite concerned about it.

**Mr J. Wilson:** I know your colleagues were unable to appear, and it is good of you to take the questioning on their behalf. You have had an opportunity to see the Progressive Conservative amendments, have you?

**Mr Graydon:** Yes.

**Mr J. Wilson:** I hope you will look over the amendments. On page 2, dealing with Bill 109, I think we tend to agree with your recommendations on the definition of "treatment" and "presumption of capacity." I really do not have any specific questions. I think your brief is short and to the point. Mr Sterling may have a question.

**Mr Sterling:** On your concern about research, it has been a concern of, for instance, the Alzheimer society. The people involved in that were, and you are, involved in an illness which does not have the answers yet, and therefore the people suffering from it are grasping, often, at whatever is available. The section deals with people who are incapable. Now, is it your contention that those people who have lost their capability should be allowed to continue a

treatment or be allowed to start a treatment during that period of incapacity? I am not that familiar with the stages. It probably affects people in a hundred or a thousand different ways.

**Mr Graydon:** The concern arises in relationship to AIDS-related dementia, where a person could be theoretically deemed incapable of making a decision, but for all intents and purposes from observation is acting as if he understands what is happening. The research we have tried to mount at Casey House has been fraught with difficulty, where we have consulted with the person, obtained his verbal consent, and returned within 24 hours for written consent to find him incapable of understanding to give consent. So it would not necessarily be for maintaining any kind of research once consent has been obtained, but for initiating research, and then possibly 24 hours later that same person could once again be able to give consent.

**Mr Sterling:** Let me put the burden on you in this way: How would you prevent the situation I think this section is designed probably more for, the situation when you are dealing with a concern about—I think that medical ethics committees take care of this; I think it is there for this reason—where you are not dealing with a disease like AIDS or Alzheimer's but something to do with the heart or whatever and there is an attempt to take advantage of a group of people who are not capable of making a decision and to convince them to participate in a research project which may have some detrimental affect on them. I think that is the way it is designed.

**Mr Graydon:** Which may have some detrimental affect?

**Mr Sterling:** To their health, their long-term health. How do you protect those people?

**Mr Graydon:** If there is some possibility of harm to the patient, then I imagine that he would need absolute protection at all times. What I am referring to is research that would be not deemed harmful and creating a mechanism where a decision-maker could give consent on their behalf. My own personal feeling is that if there is potential harm and they are incapable at that point in time, then they should be protected.

**Mr Sterling:** But is it not that in a lot of cases when you are into this experimental area, it really is not known if there are. I do not think you want to shut that off. If I were faced with a terminal disease and someone came in and said there was some prospect of some success with this, but there might be side-effects, I as a capable person would take that risk. That is your argument, is it not, part of your argument?

**Mr Graydon:** If a relationship existed between the person, between the power of attorney or the executor, if there was a relationship between him and the patient, where he felt he knew the will of the person, then I think that might be acceptable.

**Mr Winninger:** We had a University of Ottawa law professor, Cynthia Peterson, appear. You may know her. She asked that there be indicia of partnership included in the definition under Bill 108. She seemed to adopt the

same point of view that you have, that it is not necessary that there be external recognition by others of partnership but that it would be helpful to add some indicia which would indicate whether or not a partnership might be defined to exist between two people. What do you think of that proposal?

**Mr Graydon:** First of all, you are going to have to define the term; I am not familiar with the term.

**Mr Winninger:** Indicia? Characteristics of a relationship. For example, you might have several potential partners all wanting to have an interest in a particular decision as a substitute for, say, an AIDS victim.

**Mr Graydon:** This would be in a situation where the relationship has not been clearly defined by the person?

**Mr Winninger:** By which person?

**Mr Graydon:** The theoretically incapable person.

**Mr Winninger:** Yes, exactly.

**Mr Graydon:** Then yes, I think I would have a tendency to agree with her, without understanding her full position, where there was some indication of characteristics of what we would deem a relationship.

**Mr Winninger:** There may be situations where same-sex partners live together in a traditional spousal relationship and then there may be more flexible arrangements that may require further definition in order that you minimize conflicts between family members and partners.

**Mr Graydon:** Yes, that would be an interesting exercise, because we certainly experience that at Casey House, where there could potentially be several partners. We try to identify the significant other, by gathering evidence from friends around the person to see who has got the most significant relationship at that point in time. In a sense, then, we are canvassing for other persons' recognition of the relationship when the patient is unable to identify his partner.

**Mr Winninger:** I see.

**Mr Graydon:** I suppose a definition with characteristics of a relationship would be useful.

**The Chair:** Reverend Graydon, on behalf of the committee I would like to thank you for taking the time out this morning and coming and giving us your presentation.

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ELIZABETH LEESON  
JEANETTE DUFF

**The Chair:** I would like to call forward our next presenter, Elizabeth Leeson.

**Mrs Leeson:** My name is Elizabeth Leeson, and this lady is Mrs Jeanette Duff. I would like to thank the chairman and members of the committee.

Bill 8, the right to die with dignity: This is, in my opinion, a necessary and correct piece of legislation. Upon the death of my only child on September 6, 1981, I wrote my own desires for care and attention. It included my wish to be allowed death in a dignified way without the life-sustaining supports which are now used. My doctor was informed of this. I now carry in my personal belongings "A Right to Die With Dignity" form, signed and witnessed.

Each person must accept the responsibility for his or her own demise and make it known in a written or, if sufficiently lucid, a verbal way. Family members ought not to make the decision for the life-ending of another person; the emotional burden is too awesome. I agree entirely with Bill 8.

Bill 74, provision of advocacy services to vulnerable persons: I consider myself to be a vulnerable person as I am alone. Although not incapacitated, either mentally or physically, I have been isolated from my family. My husband died in 1955. We had one child, a beloved daughter, who as I have previously stated died in 1981. Three small children, my grandchildren, have been denied any contact with me, their maternal grandmother, from the day of their mother's death. The youngest child was killed at the age of four years. I now have two grandchildren who have not been permitted contact, although they are aware of my existence.

Times without number I have taken this man, my former son-in-law, to court hoping for an opportunity to be what I am, a grandmother to the only relatives I have in the world. They are my next of kin and my beneficiaries. Although an uneducated man, he has manipulated the justice system and made a mockery of both Brampton and Newmarket courts. He is not alone in his behaviour, and no matter how many judgements have been issued, he and his associates are determined that my grandchildren shall not have contact with me or I with them.

What they are afraid of I do not know, but every conceivable damage has been used against me: character assassination, harassing behaviour or whatever they can think up. A fist has even been pushed into my face. I may also add that my burial place has been taken away.

I spoke of this heartache in this legislative chamber in 1982 in the hope that someone would listen. In April 1983, amendment was made to family law which permitted anyone to apply for access to or custody of a child. Grandparents are not anyone; a maternal grandparent takes precedence after the father. Children who have experienced the death of a parent must have a mandatory, ongoing relationship with the grieving grandparents. This type of bonding is necessary for the healing process. It is entirely different from divorce. The emotions are not the same where two parents are alive. Death is final. The law must be amended immediately.

Since speaking out in 1982, many grandparents have lobbied in this building and spoken to committees regarding their wish to see their grandchildren, but their appeals have fallen upon deaf ears. The previous administration stonewalled us at every end and side and appeared uncaring of the magnitude of the situation. We had much support from the Conservative Party, which has continued to this day. The NDP, which was in opposition, was equally supportive. One member in particular, Mr Richard Johnston from Scarborough West, who is no longer in the House, had been kind and compassionate to me since I spoke here in 1982.

However, when the NDP formed the government, we began to hope for justice, but once again it appears we are a forgotten people. This is not a political issue, but denial

of human justice. Several ministers in this present government of Ontario, including the Attorney General, have studied elder abuse. It is one thing taking part in a study but quite another when one is the victim. To us, it is cruel reality.

As a grandmother, I have the normal human capacity for caring. To deny me that right is to deprive me of a reason for living. It is cruel to me and to my grandchildren, an injustice which is unfortunately all too common and which has been perpetrated for generations. I am many years past my allotted span of threescore years and 10. I have come to terms with my mortality, but have not, and shall never, adjust to being deprived of sharing a fundamental love and relationship with my grandchildren.

On page 5 of a booklet issued by the office of seniors' affairs, entitled *Elder Abuse, the Hidden Crime*, it states, "To isolate the older person from other family members constitutes abuse." This is what I speak about. I am one of the abused. Since the government is aware of this situation, which covers every spectrum of society, the time is now and must be acted upon accordingly.

I now refer to Bill 74, and would like an answer regarding advocacy. Is it possible that an advocate's intervention will succeed where the justice system has been defied in uniting me with my grandchildren? Bill 74 is a welcome piece of legislation, but I wonder if it can be effective if not protected under the law.

If Bill 124 had been proclaimed, I personally would have been pleased. I have spent thousands of dollars and even after 10 years do not see or hear from my grandchildren. The person inflicting this heartache tells the court what it wants to hear, then does exactly as he pleases. Please tell me, committee, will the advocates have power to intercede upon my behalf?

From my grandchildren and myself, I wish to thank you.

**Mrs Sullivan:** I wonder if I could repeat the question asked in this brief from Mrs Leeson to Mrs Carter. Would Bill 74, the intervention of the advocate succeed "where the justice system has been defied in uniting me with my grandchildren"? Perhaps Mrs Carter could address that issue.

**Ms Carter:** Of course we do support families and that is specifically stated in Bill 74. As a grandparent myself, while I am lucky enough not to be in your situation, I certainly feel with you and know how I would feel if—

**Mrs Leeson:** I am sorry, but you have no idea how you would feel unless you are there.

**Ms Carter:** No, but maybe I have a ghost of it, shall we say? Obviously I cannot feel it fully. But I do not think you would count as a vulnerable person as envisioned in the act.

**Mrs Leeson:** According to this, I am extremely vulnerable—elder abuse. Grandparents who are denied access to their grandchildren are classified as the top priority in elder abuse.

**Ms Carter:** I am not saying we should not help you through legislation.

**Mrs Leeson:** It is time somebody did, because 10 years is a long time.

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**Ms Carter:** But I do not think this act is the specific vehicle that would do that. Would counsel like to comment on that?

**Ms Spinks:** I think the act is to serve a wide range of vulnerable people. Certainly many of the elderly fall into the category of being vulnerable in certain circumstances in their lives. If they are experiencing a problem dealing with the system and if, in the view of the commission and the advocate, they meet that definition and are eligible for service, then of course the advocate would be supportive in helping them find the avenues to voice their concerns.

**Mrs Leeson:** What are you going to do about it? Are you going to write it into the law?

**Ms Carter:** I certainly hope we can but I think we shall have to look to doing it through a different avenue.

**Mrs Leeson:** They have been looking for 10 years. If I live another year I shall be 80. I shall not see my grandchildren; they are both under age. They are the only relatives I have in the whole world.

**Ms Carter:** I promise you I will follow this up.

**Mrs Leeson:** You have to follow it up because there are too many of us in this position.

**Mr Sterling:** I would like to thank you for your support of my Bill 8 dealing with—

**Mrs Leeson:** I support the bill. I am retired now, incidentally, and I have had it in my own family where many times I was helpless.

**Mr Sterling:** Thank you very much for your support of Bill 8, my private member's bill.

**Mr Winninger:** I take it you are trying to enforce your right to access to your grandchildren through the courts right now?

**Mrs Leeson:** I have been in court about 20 times and I can afford to go into court one more time and then I will have no money left at all. I am concerned about my grandchildren when I am no longer here, because they will have the guilt feelings of having abandoned their grandmother. My grandson is now 12.

**Mr Winninger:** When was the last time you saw your grandchildren?

**Mrs Leeson:** By court order at Newmarket court, the father was told that my grandson had to have two visits with me by the end of the year.

**Mr Winninger:** Which year?

**Mrs Leeson:** At the end of last year. The order was made on September 26. It came to December and I had not seen, heard or anything, so I contacted my lawyer and the father allowed my grandson to come and visit me. I had not seen him for six and a half years and the father's brother was with him. The father's brother was there for the two two-hour visits but would not allow my grandson to speak to me. The uncle was aggressive; he was hostile; he was nasty.

**Mr Winninger:** Have you seen the other grandchild?

**Mrs Leeson:** My other grandchild is now 19 and by law she could contact me, but with 10 years of indoctrination about this horrible grandmother who does not want her, she sent a letter at the instigation of her father to the court to say, "I don't want to see my grandmother."

**Mr Winninger:** Thank you for answering my questions so candidly.

**The Chair:** On behalf of this committee, I would like to thank you for taking the time out and coming and giving us your presentation.

**Mrs Leeson:** I wonder if Mrs Duff has something to say.

**Mrs Duff:** I just want to say one thing: I am very supportive of everything Mrs Leeson has said because I never thought I would see the day I would be in the same situation. You think: "Oh, isn't this great? I am going to grow up and I am going to have my children and then I am going to have my grandchildren I can enjoy." My case is not as bad as some others I have heard of. Some of them are really a little bit horrifying. You do not realize until you become a grandparent yourself the emotional and mental strain you go through.

**Mrs Leeson:** Incidentally, may I add that I cannot even be admitted to a hospital because I do not have a next of kin. When one is admitted to hospital we are asked, as a retired nurse, who is to be notified in case of emergency. I cannot do that because I have nobody—absolutely nobody. But I have arranged with the undertaker that I can use his name. It may sound morbid to some people but to me it is reality.

I am depending on somebody to do something about grandparent access. I get angry every time I come into these committees and I feel as if I am being brushed aside like all the other grandparents, so start moving.

**The Chair:** Thank you for sharing these experiences with us today.

#### THE ADVOCATES' SOCIETY

**The Chair:** I would like to call forward our next presenters, from the Advocates' Society. Good morning. Just to remind you, you will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Ms Cronk:** Thank you for the opportunity to address both yourself and members of the committee this morning. My name is Eleanore Cronk. I am vice-president of the Advocates' Society. I appear here this morning with Duncan Read, who is the executive director of the Advocates' Society here in Toronto, and Ray Colautti, a member of our board of directors from Windsor, Ontario.

Our comments will be initially, Mr Chairman, as you have invited us to do, very brief. They are intended to provide you with an overview of why we are here this morning and to outline for you both our support of the initiative this bill reflects and as well the suggestions we

have, which we hope will be received in a way that will allow the bill to be improved before final passage.

I do not know how much you and your colleagues on the committee know about the Advocates' Society, so may I very briefly indicate who it is you are hearing from at the moment. The Advocates' Society is a province-wide organization of approximately 1,900 litigation lawyers in Ontario. The members of the society practise as legal advocates in every forum in the province, whether it be the courts or before administrative tribunals or any dispute resolution forum of any kind. About 60% of our members come from outside Toronto, from the northern reaches of the province and as well from the southern reaches of the province, and our headquarters of the board of directors is here in Toronto.

We from time to time appear before committees such as this and others like it to provide whatever suggestions we can as to ways in which to improve legislation or to address issues we as legal advocates contend with every day in the courts and before the various tribunals before which we appear. It is for that reason, because of our experience in that context, that we are before you today.

I said initially, and I would like to say again, that the Advocates' Society and its membership at large wishes to convey its unqualified and resounding endorsement of the initiative this legislation represents. We understand the need for, and applaud the effort to provide statutory protection for the vulnerable and to provide a mechanism in a statutory way for the protection of their interests and the advancement of their rights. That is the first message that, on behalf of our membership, I wish to communicate to you this morning.

In that context, however, there are a number of issues that have arisen for our members and for our clients, many of whom have written to us about this, that we wish to talk to you about this morning. We do so specifically with the hope that it will engender discussion among you as a committee so that we can offer our assistance, if that will be of value to you, to make improvements to the bill that we think will respond to the kinds of concerns that have been raised with us.

I am going to ask Mr Colautti to briefly outline for you the principal highlights of the issues we want to talk to you about this morning. We do so orally today with the hope that you will receive from us in approximately 10 days' time written submissions that outline in more detail the nature of the concerns that have been expressed to us and our suggestions as to how you might deal with them. If you would hear now from Mr Colautti, I would be grateful.

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**Mr Colautti:** There are three basic concerns we have and we put before you concerning the act as it is presently drafted. The first one concerns the function of an advocate under Bill 74. It is largely defined in various provisions under Bill 109, the Consent to Treatment Act, and Bill 108, the Substitute Decisions Act. The provisions in those acts, in very specific instances where there are certain applications being made that may affect the question of the competency of a person under review, empower and require an advocate to give advice to vulnerable persons which often

involves fundamental rights of self-determination over the person's self and his or her property and often impinges on or involves matters that may be legal in nature. These are some of the most difficult questions that arise in the practice of law, sometimes, involving a person's competency. It can arise in a litigation context in a whole number of forums, and it is impossible to establish any generalized rules, because it goes on a case-by-case basis. Consequently, it is very important to appreciate fully and completely what the person's legal rights are and how those legal rights may be affected by the proceedings the person may be facing.

The legislation should therefore spell out in greater detail than it does now what the function of the advocate is going to be and the fundamentals of the training the advocate should have. The act as it is drafted now is silent as to the qualifications of the advocate. We are a bit uncomfortable with that. It is important that they be exposed to some professional knowledge and training. We are not necessarily suggesting, of course, that they have to have a law degree, but they have to have access to people who can give them the proper advice in situations that may arise. The qualifications and the background, therefore, of the advocate should be stated in the legislation in some fashion, and the qualifications and background to serve on the commission should also be indicated.

The second concern we have is rather a serious one, and it concerns the rights of entry conferred on advocates under sections 16 through to and including 23 of the act as it is drafted. There are two types of rights of access. One relates to facilities where a person is in a facility as it is defined in the act and another one is where he is in premises which very obviously includes a home. There is no reason why the advocate should not have access to the person when he or she is in the facility, but there may be reasons that are very difficult to ascertain at this time why there have to be limits on the right of access in a private home. The way the act is drafted now, it would be an automatic offence if the advocate, on producing credentials, is denied access to a home. There may be very good reasons why in a particular instance a person may be denied access to a private home. Rather than dealing with it after the fact in the context of a prosecution for denial of access, it should be dealt with up front, and we would suggest a different kind of mechanism than is presently proposed in the act.

The kind of mechanism that could be considered would be that if there is a request to access somebody who is in a private home and a denial, there should be a very summary and simple form of application to a court of competent jurisdiction. The Ontario Court (General Division) has particular expertise in the past in dealing with incompetency questions. An application should be made to a judge to gain access, on notice to all persons who may be affected. That way you do not have the creation of an automatic offence, and the court can balance the interests of all parties and make the proper order, in a very summary and quick fashion, to provide for the right of access; that is, would give a judicial scrutiny to this right of access to a private dwelling and would protect the individual

family's right to privacy. That is a significant concern we have with the legislation.

The third concern we have is the use of the term "advocate" in the act. The O'Sullivan report very clearly spells out the definition of "advocate." One of the very first definitions it considers is the connotation in the public mind that "advocate" connotes somebody with legal training who presents briefs on behalf of clients before courts and administrative tribunals.

We have some concern with the use of that terminology as it exists in the act, and as the O'Sullivan report has suggested, what the act is really talking about is a type of social advocate. Even if that term were used, I think it would diminish in the minds of the public the confusion that exists. I can tell you, and Mr Read can comment on it personally, about the confusion. He gets a number of phone calls in any given week confusing our society with the kind of advocate proposed by this act. He gets a lot of questions from people who are looking for a social advocate and are calling the Advocates' Society. The confusion in the minds of the public is apparent.

Those are essentially our concerns, and we will detail them to you in a more detailed written brief in 10 days' time.

**Ms Cronk:** When I began my remarks, you may have noticed that in describing the Advocates' Society to you, I described us an organization of legal advocates. That is a term and a qualifier I am not used to using. I did so quite deliberately today to underscore the last point that Mr Colautti just made to you.

Quite literally, since the introduction of this legislation, our switchboard has been ringing off the wall. Because of the confusion created by the names, people who are familiar with the legislation believe that it is the Advocates' Society. We have done our best, in a non-delegated sense, to be good representatives of those introducing this legislation in fielding those calls, but I tell you as a fact that the confusion is there. That is why I referred to legal advocates, so that it would underscore the point I knew Mr Colautti was going to make to you.

As we understand it, the objective of this legislation, and you have heard me say already that we support it, is to ensure that there is an advocate—perhaps there is a better qualifying adjective to introduce, but an advocate that should not be taken to be solely or at all a legal advocate, because of course it may not be either; it is a form of social advocate.

You may design a different qualifying word or descriptive to include in the legislation, but we urge you to do that so there is not a misunderstanding at large in the minds of the people who are to be protected by this legislation about who these advocates are. That is the first point I wanted to underscore in a practical sense, because that is happening already. I am not looking forward to a future without that kind of descriptive, when I will simply install a call button that puts all these calls on call forward to your respective offices. I say that, obviously, with some facetiousness.

We are concerned, as Mr Colautti points out, with the rights of access. We see a fundamental conceptual difference between right of access to facilities and premises at

large and to private homes because of the familial relationships that exist and because of the consequences for the family unit in the event that access is sought and denied. We urge you to consider a different process by which a denial of access can be reviewed when you are talking about the private home setting than for the public institution or facility setting. That was the second point.

Finally, to comment on the first point Mr Colautti made—I am dealing with them in reverse order—we think it most important, so that this legislation be certain and be understood by those who will work with it, that the duties of the advocate be clearly articulated. At least the rubric, the fundamentals—we do not suggest the details, but the fundamentals of the training that advocates are to receive should be spelled out in the legislation itself. The legislation should speak generally to the qualifications as minimum background qualifications of the people who are going to function as advocates and the type of people whose qualifications and experience and background you wish to see on the commission. We think that most important.

We offer those suggestions, which we will develop in writing, in an effort to generate discussion that we hope will result in improvements to this legislation. We invite any questions you may have.

**Mrs Sullivan:** We will certainly be looking forward to your written remarks, and I think the oral presentations you have made this morning are useful. The question of competency determination has been put forward by other groups, including those in the health care field itself, and that is one that is a matter of some concern. We concur with your view that the duties of the advocates should be clearly articulated and that their qualifications should be spelled out in the legislation rather than through regulation, where there is not the opportunity for public discussion and debate over the role, place and duty of the advocate. We also believe there should be an accountability built into the legislation for the advocate who is performing whatever duties are specified.

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**Mr Sterling:** Why do you not rename your outfit the barrister's society?

**Ms Cronk:** It is an interesting idea, Mr Sterling. It would create some obvious discussion. "Discussion" is an interesting word to use in reply.

**Mr Sterling:** Okay.

**Ms Cronk:** I do not think it solves the problem, in any event.

**Mr Sterling:** I know. I say that mostly in jest.

**Ms Cronk:** I thought you were reading the statement in defence to the passing-off action there, sir. I was not quite sure.

**Mr Sterling:** I have had great concerns about the right of entry. So little has been said about protection of the private home. I suspect that had we introduced this legislation five or six years ago as a Conservative government, the New Democratic Party would have been at us with such a vociferous attack that we would not know where we

were. But notwithstanding that, do you not think it should just go through a warrant process of some sort?

**Mr Colautti:** I do not think a warrant process is necessarily the way to go. Obviously if there is a denial of entry, there must be some reason for it. The warrant process does not fully allow for—and that kind of court is not really set up for—dealing with the kinds of disputes that may arise, whereas a summary application to the Ontario Court, simply supported by way of affidavit evidence, can set out very clearly what the objections are.

**Mr Sterling:** Okay, I understand that argument. I am sorry to cut you off, Ray. What about the time factor here? The argument is that the advocate arrives at the door and hears shouting behind the door. He wants to go in and help the vulnerable person. That is why the warrant process, notwithstanding there are different considerations—

**Ms Cronk:** If I could just respond, and Mr Colautti may add to it, it seems to us that what you need to be assured of under the legislation is a summary, peremptory procedure which will allow fast access to a judge for determination of an access denial issue. That is what you need. You have to be assured of the time line, that it is going to happen quickly.

Having said that, really what is behind our submissions on the deficiencies of the warrant approach, if I could put it that way, is that very often the warrant approach, if I can direct my comments at large, is designed for access to documents. It is designed for access to records. It has rarely been used in the past in the forum contemplated by this legislation, for access to people. It is quite a different balancing exercise, in our view, as to the judgement that has to be exercised for that.

There are analogies under other legislation, including in the civil litigation context, whereby summary, peremptory procedures are available to get before a judge of the Ontario Court (General Division) quickly for a fast decision on an issue like this. There need not be a time loss element to it. It is a question of where you go and whether you go on notice. We are very concerned to make it clear—and I do not overstate it when I say—in the interest of natural justice, that there be a notice requirement for this kind of a review of a denial of access. That is the concern. It is your forum. It is your time line, and it is the notice requirement that we are concerned about.

**Mr Colautti:** The notice should be the general rule. Where there are situations such as you are adverting to where there is an emergency, then there can be a mechanism built in for a very quick application without notice to a judge to obtain the necessary orders. These kinds of things are very standard in the courts right now, and it would not be anything unusual.

**Mr Sterling:** What do you do on Saturday night?

**Ms Cronk:** If you have to get to a judge on the weekend, you can.

**Mr Colautti:** I have had occasion myself—not in this particular area—to have to find a judge on a weekend. I simply pick up the phone and call him and get hold of him.

**Ms Cronk:** Ex parte applications to justices can—obviously it is not as easy on a Friday. If you have to do it, it can be done.

**Mr Colautti:** It does not have to be done in a courtroom.

**Mr Sterling:** In your brief to us, could I ask you to consider what you would deem an adequate complaint process for individuals who were upset with the advocacy services? I am very much concerned, perhaps suspicious of state-run advocates of any kind. I do not like the idea of civil servants going out without very much direction and saying, “I am going to save somebody and protect his rights.” I have concerns about that, from the point of view of both a friend of an incapable person and the incapable person himself. I view other professions as having much stricter disciplinary actions that can be taken against them, through the law society, health care professions etc. Under this one it really does smack of Big Brother in a lot of ways and I am very much concerned about that and would ask you to do that in your brief to us.

**Ms Cronk:** We would be pleased to do that.

**Mr Sterling:** Who would sit on the disciplinary board and what remedies could be taken. Can I ask you one other question you might consider? If advocates retain the right of entry, what would be adequate compensation for the wrongful use of that power? Should the advocate be personally responsible? Should he be protected from civil litigation? Should there be punitive damages?

**Ms Cronk:** Will you allow us to consider that in written form as well?

**Mr Sterling:** Yes.

**Mr Colautti:** That is a very difficult question to answer.

**Mr Sterling:** It might be somewhat philosophical, but you may have some knowledge of people who are hired by the state who have civil protection but are not given these wide powers as well.

**Ms Cronk:** It is precisely because of that undercurrent to the issue that we are concerned that there be a mechanism to get to court to review a denial of access, because the consequences for the advocate and the persons affected by the advocate's attempted entry will get you into civil court overnight unless there is a threshold judicial consideration of whether he should have been there at all. That is one of the problems that is behind our thinking.

**Mr Sterling:** That is right, yes.

**Ms Carter:** I will try to speak to your specific questions. First of all, as regards who the advocates will be and what their training will be, it was the intention in drafting this bill to leave that vague in the sense that this is not seen as something that is being set up by government so much as something that is going to be at arm's length, and hopefully free of conflict of interest and independent. So in section 13 we have set up the mechanism for the appointment of an appointments advisory committee. We have specified the groups that should be represented on this committee and we have left it to them to appoint the commission, which will in turn, of course, appoint the advocates. We have tried to give it a consumer orientation; that is, it is the people who are going to be most affected by the

work of this commission who will have the input as to both who is going to be on that commission and what kind of training they will have. So I think the omission is not that we have been sloppy; it is that we have deliberately wanted it to evolve in that kind of way. You might disagree with that.

**Ms Cronk:** We recognize that, Ms Carter.

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**Ms Carter:** Regarding right of entry, I feel there is overreaction to this in a sense because what we are thinking about is one individual going to a house and requesting to speak to somebody who lives there. If that person, the person who may or may not need the help, asks the advocate to leave, he will immediately do so. So there is no pressure in that sense. If there is not found to be a reason to be there, then the person will immediately leave. All that he is asking to do is to speak, as privately as possible and without interference, to that person who lives in the house.

I am afraid if that were formalized, if notice had to be given, judges involved and so on, if there actually was somebody vulnerable in that house who may be suffering at the hands of other residents of that house, for whatever reason, the situation within that house might evolve in a way that led to further abuse of that person. In other words, I do not think there should be all this song and dance. I think it should happen quickly and quietly, and the advocate should be able to find out if there is a problem. If not, then they would leave, and as far as I can see no harm would be done. It is not like police breaking in and conducting a search or hauling people off to jail or whatever; it is just somebody wanting to come in and see.

**Ms Cronk:** It was for that reason that our comments were directed to what you do when access has been denied. It seems to us, to come back to the fundamental rationale of this, that this legislation is conferring extraordinary powers on citizens who previous to the introduction of this legislation did not have powers of this kind. So in that sense it is highly intrusive although the objectives are clearly laudable.

What we are suggesting is that if one assumes that those with the power you describe will exercise it in the way you hope—in a way we all hope, and that is with discretion, courtesy and responsibility—if access is denied they will immediately leave. What we are suggesting is that from that point forward there should not be the automatic kick-in of an offence under the statute, which is what is the case now from a legal interpretation point of view, and that they should not be able to simply go out and get a warrant, without more, to compel entry in the face of an initial refusal. It is simply a protection.

**Ms Carter:** I would like to ask counsel to clarify that point.

**Ms Spinks:** If you refer to section 34 of the bill, it creates an offence only for denying access to a facility, not to private premises, for that specific reason you mentioned. Therefore, the recourse of the advocate is to seek a warrant, and in normal circumstances that warrant will have to be made only on notice.

**Ms Cronk:** Thank you very much for that clarification. With respect, then, not to the automatic offence part of it, and I thank you for pointing that out because it is important obviously in light of the submissions we have made and the concerns others have expressed, it is equally important that compulsory entry in the face of an initial refusal not be permitted without the proper weighing of the interests.

I suppose, wearing a lawyer's hat, we all bring to this the experience that we have. Mine happens to be in the law, so I bring that background to my analysis of it, as the three of us do. When you design legislation of this kind, I would suggest what you must be concerned about is not the proper exercise of authority but the improper exercise of authority. It is, therefore, not the responsible, courteous and informed carrying out of the power that you have to be concerned with; it is the improperly carried out power. So what we are asking for is a protection to ensure that there is a check mechanism, that there is just another moment to pause before there is that compulsory entry, and the way to do that is with someone who is very used to looking at those issues, and that is a judge of the Ontario court.

**Ms Carter:** As I said, I think that does seem to be largely covered.

Your other point was the name. I like the name.

**Ms Cronk:** So do we.

**Ms Carter:** Can you suggest anything else we could use? I feel it is the appropriate word, and I am not quite sure what else we could call it.

**Ms Cronk:** We were not suggesting that it was necessary to abandon the use of the word "advocate." I personally have considerable affection for the term for all kinds of reasons. We were suggesting that you use a descriptive, an adjective, before it to make it clear that you were not talking necessarily about a legal advocate, ie, a lawyer. So if you called it a "social advocate," if you called it something else that was consistent with the language in your bill, I believe it would reduce what is very real confusion.

**Ms Carter:** It is understood these people will not be lawyers.

**Ms Cronk:** I would hope that some are, but maybe not all. I would not like to think we were automatically eliminated.

**The Chair:** Ms Cronk, Mr Read and Mr Colautti, on behalf of this committee I would like to thank you for taking the time out this morning and coming and giving us your presentation.

**Ms Cronk:** Thank you for your time.

**The Chair:** Note that answers to the questions to ministers were handed out to all the members of the committee.

Now we will proceed to the deferred motion by Mr Sterling.

**Mr J. Wilson:** Just a point of order, Mr Chair: In reference to the answers provided, particularly the answer concerning the current advocacy expenditures by the government, I do not find the paper that has been presented today to have sufficiently answered the question that was asked. The question that was asked is referred to in one of

the paragraphs, where it says it would be very difficult to list all the groups outside government which are receiving government grants. I do not find it sufficient to say that just because it is difficult to list those and you would have to contact various ministries, we should not be provided with such a list.

It also seems to imply that many of these people who have appeared before this committee on behalf of their groups are being told by this response that they in fact do not do advocacy, and the government does not see that they do advocacy. Some of the major groups missing are the—I forget the exact name, but we had them here yesterday—the child advocacy office at Comsoc, and the adult protection service workers are not even mentioned in here. Mrs Sullivan had mentioned a few more to me in private. I would not be very proud of having prepared this response if I were the one who had done it.

**Mrs Sullivan:** Mr Chair, if I could speak to that point of order as well, I think people on this committee who have read, for example, the O'Sullivan report, seen that report—an examination of advocacy services provided through government funded sources—many of those agencies provide legal services through the legal aid services, but indeed there are social advocacy services provided through many of those services.

I think the question Mr Sterling put was one that has been a matter of real interest in terms of the drafting of the bills, right from the days before the O'Sullivan report came forward. I suppose what we are looking for, and I think that the government members would want to have this information too, is an indication of what is in the field now, what the extent of the services are, what the public funding is now.

One particular model of advocacy has been put forward in Bill 74, and then that model has been integrated into Bill 109 and Bill 108. The concern is if that is the appropriate model, if there could be adjustments to Bill 74 based on existing services. The intent of Mr Sterling's question was not to bring into question the concept of advocacy itself but to look at the appropriate models, and because the government has not done its own examination of the cost-effectiveness of the extent of duplication and possible duplication, the committee is asking for the government to do that, so that the information can come forward.

We are very surprised—I think all of us—that there have been very vague notions of advocacy, very vague notions of the cost of this entire Advocacy Commission. That is the kind of information it seems to me is important, not only in the consideration of the legislation but in the consideration of whether this particular model will work, and whether amendments to the bills might be useful to introduce an adjusted model that can be done through amendment. I think this information Mr Sterling asked for was material that we wanted, that we think is important, and this is just an inadequate response. I feel very strongly about that.

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**Mr Sterling:** If the ministry cannot identify the other advocate services, perhaps other members of the commit-

tee can help me identify the ones we have heard about here and that we know about in our own communities. Perhaps then the ministry can go out and try to get a best estimate of the resources that are being put there and whether or not it is anticipated that those resources are going to be reallocated to the Advocacy Commission.

I am told, for instance, that most hospitals have a patients' advocate within their own hospital structure. Is it the intention that that advocate remain and do that work and that there be another advocate coming in and that there are going to be two advocates dealing with the patient, or is that going to mean a cutout of that person in terms of the hospital budget or whatever? That is one area I would like to know about, and I understand it varies from hospital to hospital.

Based on the evidence before this committee—I think 40% was the figure used by the adult protection worker I asked a question of—40% of their time is taken up by advocacy. I would like to know what it costs for the 175-odd adult protection workers and the administrative structure surrounding them in this province. Those are two examples that I know of off the top of my head, and perhaps Mrs Sullivan and other members of the committee know of other areas.

The lawyer who was with the children's rights group that was here does work with the children's hospital. I do not know how he bills his time, whether he is hired by the children's rights group, whether it is funded as well and whether or not that funding will end when the Advocacy Commission is going full tilt. I think it is important that we know that as well.

With regard to the legal aid clinics that are set up, is it the intention to cut back their funding as a result of these advocates coming and taking the place of those advocacy groups as well as the legal aid clinics?

**Ms Akande:** I think part of this discussion has to revolve around one of the issues that was mentioned by the previous group, the Advocates' Society that just came in on matters of very specific definition of advocates, what their functions are and who exactly they will be. I have found in the past that the term is used most generally by a lot of groups. They define their particular form of advocacy, which may or may not conflict with or overlap with what we are specifically describing here.

The other thing I want to mention in relation to that is at the back and it is a part of the same point. On page 5, it says in this last paragraph, "There are no other ongoing specific advocacy services of a non-legal nature," and I think there is a whole question that you are speaking to also, that we are not certain about what particular services they are referring to here because of the fact that that term "advocacy" is used so generally and so widely by so many different groups to mean so many different things. It is funded differently by different groups, and some of it comes into government and some of it does not, but I think that is one of the things we will have to do in order to answer this.

**Mr J. Wilson:** Thank you, Ms Akande, I think your points are excellent. Regarding the second briefing notes that have been given to us entitled "Documentation of the Prevalence of Abuse," I was just wondering if it was possible—

because in the section, "Abuse Among People with Disabilities," I do not see any reference to the sample size. It is all done in percentages as far as I can see, having read the four or five pages, and I would like to know what the sample size is. It would be much more helpful in interpreting this information.

**Ms Carter:** I agree with what Mrs Akande has said. I think this is a unique service we are suggesting, so to say one should equate it with things already in existence is a little fuzzy at the edges. Some people styled "advocates" would not be so under this definition, for example.

**Mrs Sullivan:** Could you explain that?

**Ms Carter:** The group that was just here presenting to us are advocates. This is a wide term that includes a whole range of different functions. I would say there is not likely to be any overlap, for example, with these people who in fact are lawyers. I would like to ask the Chair if he would invite the ministry to expand on this and let us have some further—

**The Chair:** I was going to suggest that we invite the ministry to try again, taking a look at some of the things that have been brought up by the members.

**Mr Sterling:** Mr Chairman, because Mr Winninger has to catch a plane leaving very shortly, I would like to place my motion. I will keep my remarks very brief.

**The Chair:** Mr Sterling moves, given that many parties and presenters before the standing committee on justice have acknowledged that major changes are necessary to improve and enhance Bills 74, 108, 109 and 110, that the standing committee on justice reconvene for public hearings not earlier than two months after the government amendments to these bills from the Ministry of Citizenship, the Ministry of Health and the Ministry of the Attorney General have been tabled and widely circulated to enable all interested parties the opportunity to study and assess the government amendments before this committee proceeds with clause-by-clause examination of the bills.

**Mr Sterling:** That is my motion. I think it is self-explanatory.

**The Chair:** Discussion? Seeing no discussion, all those in favour of Mr Sterling's motion? All those opposed?

Motion negatived.

**The Chair:** Thank you. Seeing no further business before the committee today, we adjourn until Tuesday, March 24 at 10 am.

The committee adjourned at 1238.

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 Spinks, Trudy, Ministry of Citizenship

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## Legislative Assembly of Ontario

First Intersession, 35th Parliament

## Official Report of Debates (Hansard)

Tuesday 24 March 1992

### Standing committee on administration of justice

Advocacy Act, 1992,  
and companion legislation

## Assemblée législative de l'Ontario

Première intersession, 35<sup>e</sup> législature

## Journal des débats (Hansard)

Le mardi 24 mars 1992

### Comité permanent de l'administration de la justice

Loi de 1992 sur l'intervention  
et les projets de loi  
qui l'accompagnent



Chair: Mike Cooper  
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# LEGISLATIVE ASSEMBLY OF ONTARIO

## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

Tuesday 24 March 1992

The committee met at 1014 in committee room 1.

### ADVOCACY ACT, 1992, AND COMPANION LEGISLATION LOI DE 1992 SUR L'INTERVENTION ET LES PROJETS DE LOI QUI L'ACCOMPAGNENT

Resuming consideration of Bill 7, An Act to amend the Powers of Attorney Act; Bill 8, An Act respecting Natural Death; Bill 74, An Act respecting the Provision of Advocacy Services to Vulnerable Persons / Projet de loi 74, Loi concernant la prestation de services d'intervenants en faveur des personnes vulnérables; Bill 108, An Act to provide for the making of Decisions on behalf of Adults concerning the Management of their Property and concerning their Personal Care / Projet de loi 108, Loi prévoyant la prise de décisions au nom d'adultes en ce qui concerne la gestion de leurs biens et le soin de leur personne; Bill 109, An Act respecting Consent to Treatment / Projet de loi 109, Loi concernant le consentement au traitement; and Bill 110, An Act to amend certain Statutes of Ontario consequent upon the enactment of the Consent to Treatment Act, 1992 and the Substitute Decisions Act, 1992 / Projet de loi 110, Loi modifiant certaines lois de l'Ontario par suite de l'adoption de la Loi de 1992 sur le consentement au traitement et de la Loi de 1992 sur la prise de décisions au nom d'autrui.

**The Chair:** I call this meeting of the standing committee on administration of justice to order. Just a reminder to the committee members that there will be a subcommittee immediately following the proceedings this afternoon. We will have some things we have to discuss.

#### WITNESS

**The Chair:** I would like to welcome our first presenter. Good morning. As soon as you are comfortable, could you please proceed. Just a reminder first off that you have a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and answers.

**Witness:** I am not a political person. I am usually a very private person, and this is the first time I have done anything like this, so if I make any errors, please bear with me.

I felt these bills were very important. I have been doing some research, and I realized as I went back in my research that most of the people who were doing presentations or were consulted before the bills or before changes etc were always people who were in the health field, not other fields, were administrators of hospitals, professional associations, unions, agencies and those types of people, and the people who have these things done to them, for instance, the aged, the mentally retarded, the mentally ill,

very rarely have a chance to have any input. I think the input has only been recent.

I think that should be changed. I think other people should have the input as well, because very often the associations may represent a lot of people, but there is not a unitary view. People who disagree do not come up here and do not say it; they say it among themselves or to people like me and various other people. So I think more weight should be given to other people.

**Mr Poirier:** Excuse me one second, please. I presume the person in front of us has chosen or asked not to be identified?

**The Chair:** That is right, Mr Poirier.

**Mr Poirier:** Okay, fair enough. Thank you. Sorry to have interrupted you.

**Witness:** I have talked to people and have friends in the health professions and have met people and have friends who have been labelled mentally ill, retarded and the aged. They have told me many things, but first perhaps we could look at the stereotype. The stereotype of all three groups is usually people who are not too bright or people who are damaged, who are somehow not quite the same as the rest of us. I hope that some of you go to see Dr Linus Pauling, who is coming. He is over 90 years old. He is still active, and he is still bright. There are many aged people like that. Some of those people end up in homes for the aged. The same is true for the retarded. Many people have been misdiagnosed, and until it comes to light through the media, we do not know. The mentally ill are constantly misdiagnosed.

I think the "right to consent to treatment" should be changed to "choice, the right to choose" one's treatment, whatever it is, based on being given all the treatments; not the pertinent ones or relevant ones. But all of the side-effects and benefits, not just the minor ones or the ones that might be relevant to the patient or the old person or whoever, should be put in written form as well. That way the person could get a second opinion if necessary.

Some people want to force treatment on people. I think that no one should ever have any treatment forced on them. I think that is against one's rights. Often people complain about their treatment. I think if any of us here had some of the treatment, we would complain too; things like Posey chairs being used in homes for the aged. There was a woman who owned an old age home who was put in a Posey chair. After she was put in the Posey chair she decided she would never use it again. I think very often until the people themselves have experienced the situation, they often do not know. I do not say that they are malevolent. I know some very good people in the field and some terrible people; I do not know them so much as I have heard about them.

I do not think people should be certified or in any way put in any institution without having the right to go before the law. There are people in these institutions who have never committed a crime. They may have had parking tickets or something minor, but that is totally different. I am talking about criminal offences. I think those people should have the right. As things stand now, in some cases they have a right to go before a review board within the facility or whatever, but it is after the fact. Often they have been treated with drugs that affect them and they cannot think, they cannot function. Then why should a person be—I was going to say “incarcerated,” but put into a facility, have something done, be interviewed, and sometimes these interviews are interrogations. If you do not want to respond, you are said to have a poverty of thought and various other things. I think that is very unfair whether a person is an old person or mentally ill or anything. People are presumed to have less capacity if they have certain labels. I am sure if any of the people here had been psychiatrized or whatever, they would not want the label to be known to their colleagues or to their opponents or whatever. I think that is very important.

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It is cheaper maybe to have the doctor sign you in, but sometimes the doctor is only a resident. Sometimes it is another health care provider. I tried to find out the definition of a health care provider. I finally found out it could be anybody. It could be a nurse's aide, an orderly, anyone. Now it is a doctor. Before, a long time ago, you could only be certified for two reasons: for homicide or suicide. Now somewhere along the way it is also if you cannot look after yourself.

I have more to say on this. I have to go on to the others because I am running out of time. Maybe you could read my submission. Please do, because I am not only talking on behalf of myself; I am also telling you some of the things that people have begged me to help them with. In the past I have never had the opportunity. The health care providers have also told me things they would like someone to do something about.

One of the things is that drugs are used in all three facilities in order to subdue and not for treatment. I think that should never be used. When I was an undergraduate, psychosurgery was frowned upon by the whole medical profession and everybody else and so was electroconvulsive therapy. Somehow there has been an increase. I do not know whose attitudes have changed but damage is still there. There was an excellent study done in I think 1985 by the government that indicated how much damage was done, but we are still giving ECT. I have heard—I do not know if it is true—that psychotherapy has been dropped, is not going to be paid for. Perhaps we should consider whether we should be paying for ECT the purpose of which is to give people seizures, grand mal seizures actually, and if it does not work the first time you do it again.

I have met some of these people. When they are not given a neurological workup and their histories are done incorrectly, people die. You do not hear about this. If you really honestly want all this done to you I do not say I am going to prevent you. It is your choice, but I think it should

be an informed choice. You should know not only the pertinent side-effects but all of them. You should know the other choices as well, and sometimes people are only given that one choice, depending on age, sex, socioeconomic, the whole thing.

I should get on to the patient advocates. That is absolutely necessary. I had planned to come here but I was not able to, so I read some of the Hansards—not all of them; I wish I had. Some people are saying: “Well, these advocates won't know anything. Why give them the records? Maybe we should have a pilot study.” We have had a pilot study for almost 10 years—I am not sure, nine years—and this pilot study has saved many lives. It has also improved the future of some people. Some people have been so damaged that you cannot improve their lives very much, but you can a little.

On the patient advocates, I also have read a lot about it being adversarial. It is only as adversarial as the institutions and the providers of health care—I forget the word that is used in the act—make it. I think many of the staff are very happy to have the advocates. They have someone to bounce their ideas off or to talk to, because they are afraid to say something because with their union or association they might lose their job or suffer in other ways.

I admire Dr Martin for coming down here. He is going to get a lot of flak from his fellow doctors and I think he was very courageous to do so. Too bad other people have not done so, but I thought, “Why don't you do it?” But some people, if they are not there, someone else will come along. At least they can do some good. So I cannot blame them.

I think advocates should be in all of the hospitals. Right now it is only in the 10 institutions. I think not only for people who are incapacitated, but also for any—I am running out of time.

In the Hospital for Sick Children you could have used the advocates because when little Steven Yuz died, I think that was an unnecessary death and it was determined the problem was psychogenic. It was on the X-rays. Many people said it was incompetence of the doctors. Those three doctors are still practising. They never lost anything. The little boy was brilliant, he was a beautiful eight-year-old child who might have been a doctor now. He was not the only person to die; many do.

Also, the 23 or 32 children who died in the cardiac unit, not all those children might have died if the parents could have talked to an advocate. Some people did want to; instead, they talked to the volunteers and something, but the volunteer cannot do too much besides listening and being supportive.

I think perhaps I should let you ask questions. I would appreciate it if you could read what I have to say.

I also do not think that anybody who is providing the treatment should be certifying the person, because they want the treatment and if they get a second opinion they will get someone who wants to do the same thing. If you do ECT you are not going to have someone who does not want to do ECT to support you. So I am not saying these people are bad. They do very good things but sometimes

they do not. There was another important thing that I cannot think of right now.

**The Chair:** Thank you very much. I will assure you that each of the committee members will be receiving your brief once it is sent in and I am sure they will all read it. We have time for about four minutes for each caucus for questions and comments.

**Mr Poirier:** Pertaining to what you claimed for forced treatment, of course we understand what you are saying, that nobody should be forced to receive the forced treatment. Fair enough. How do you feel about the proposal from some of the schizophrenia people who claim that when their mind wanders and they start refusing to have their treatment that they think they need when they are in a sane mind—would you feel comfortable if they could write a piece of paper that would state, "If you find me and I claim to not want to take my treatment, when I was lucid and sane of mind I know that I wanted that treatment, here's the treatment I want, here's where I want it, how I want it, what I want, and please give it to me even though I claim I don't want it"? Would you feel comfortable with that?

**Witness:** Sometimes people change their minds. I think perhaps that kind of paper should be taken into consideration, but I also wonder if that person was here to speak to you, I wonder in what way he was coerced. Was he told, "Well, if you do this you can stay at home; otherwise you're out on the street"?

There is a thing called tough love which is really rejection, so you are rejecting the people who have already been rejected and you toss them in the street. You do not let them come home because this is a way of treating a person. I think positive treatment helps. There are many ways of treating schizophrenia.

You have obviously—I am sorry, obviously, I should never say that. You apparently have been told about one side. There are other treatments besides the neuroleptics and there are other things besides a genetic marker. You hear, "We want a genetic marker to get better drugs." There is another edge to that. Why do you really want a genetic marker? It could end up where you are having people aborted or having people sterilized, as was done in Alberta with the mentally retarded. It was frowned upon afterwards because these people were found not to be mentally retarded. I also know of a man who was called schizophrenic for 17 years and then, lo and behold, he became manic-depressive. This poor man was possibly neither. He was also very bright and his brother was a doctor. He had joined the Hare Krishna movement when he was young.

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When you listen to the words, if you know what the words mean, that is not word salad or any of the other terms. People are often misdiagnosed. Are you going to apply this to other people? If that person really wants it, then I am not going to say no. That is what I mean by freedom of choice. But if a person does not want it, and if he decides to change his mind—you see, I often wonder why they give a major tranquillizer, a neuroleptic rather

than something like Valium. Valium calms down the butterflies; the neuroleptics often increase them.

**Mr Poirier:** But I did not specify which treatment. That is not for you and me to determine right now.

**Witness:** That is what I am trying to say too. I am not determining anything.

**Mr Poirier:** Nor am I. I am not supporting one treatment or another. I am just claiming the person has described the treatment he or she wants and maybe also the list of treatments he or she does not want.

**Witness:** Yes.

**Mr Poirier:** That is fair with me. Would you be comfortable with that?

**Witness:** Provided it is done freely.

**Mr Poirier:** Of course.

**Witness:** Provided also that the person has been told of all the other treatments. For instance, orthomolecular treatment is high doses of vitamins and minerals. The psychiatric profession does not like this treatment. However, they give lithium, which is a mineral, in very high doses. When two milligrams is what you have in input, they will give as high as 1,800 for a small person. The therapeutic dose is close to the toxic dose. I cannot understand anyone—not only myself, but many people cannot understand why you would decide the therapeutic dose not on observing how a person is acting, but on blood levels. If you give a person who is depressed a high dose of anti-depressants, he gets high. Then you say a person is high and low and then maybe he is manic-depressive. Once he gets that diagnosis you cannot get back to an anxiety reaction or reactive depression, which is more like a neurotic. I am sorry.

**Mr Chiarelli:** I am a bit confused. Did you submit a written brief to the committee?

**Witness:** It will be coming.

**Mr Chiarelli:** Okay. We will look at that when we receive it. I heard you loud and clear on the issue of advocacy. You support the principle and the concept of having advocates assist people under a range of circumstances. What I am not clear on, from your submission, is whether you support Bill 109, An Act respecting Consent to Treatment. That act itself has provisions whereby medical practitioners and people in the health care field have certain responsibilities with respect to treatment or people who have incapacities.

I take it you have gone through and read Bill 109, An Act respecting Consent to Treatment, but having made your submission I am still not sure whether you support the provisions of this legislation, whether you want them less restrictive or more restrictive. I am not sure what your position is with respect to Bill 109.

**Witness:** I believe you said that was consent to treatment?

**Mr Chiarelli:** Yes.

**Witness:** Okay, I believe I said it should not be consent to treatment, it should be choice of treatment.

**Mr Chiarelli:** So you disagree with Bill 109.

**Witness:** I do not disagree with it totally, I think it should be changed in order that the person has the choice. Like the man this gentleman described, that person should have a choice and so should other people. It should be what you choose, not consenting to a certain number of treatments, because very often you are only given one treatment, that or nothing.

**Mr Chiarelli:** Do you accept—

**Witness:** By the way, I do not think any health practitioner should be absolved of liability even when a person consents to treatment because generally people are not doctors, they do not have access to the information. I think everyone should be given access to information. I am just sad that some doctors think patient advocates should be personally liable, while they should not. I think they should not, especially in the case of the Yuz child. They only got three months' censure.

**Mr Chiarelli:** Can I ask just one short question?

**The Chair:** No preamble?

**Mr Chiarelli:** No preamble. Do you think there are certain people who are incapacitated to such an extent that they cannot exercise a freedom of choice and that there have to be health practitioners who respond to that?

**Witness:** I do not think health practitioners should be making the decisions, simply because health practitioners are saying, "We want this type of treatment for you." Very often people, especially the elderly and people who have other labels, are immediately certified as incapable. I do not know all the various terms. No, I think they should provide it, perhaps in conjunction—I do not mean never. If a person has a good relationship with the doctor and the doctor gives all the information, yes. You do not need it, but—

**Ms Carter:** Thanks for your presentation. You sound like a great supporter of the spirit of our legislation, because what we are helping to do is to help people get what they want. As you probably realize, Bill 74, the Advocacy Act, is for advocates to go to vulnerable people, find out what their wishes are and help them to have those wishes carried out, and also to find out things that are wrong with the system and get something done about that.

We have heard from representatives of the kind of group you are speaking for—the disabled, People First, psychiatric survivors—so I think we have a fairly balanced view of that.

In Bill 74 we have a list of the categories of people who are going to be appointed to the appointments advisory committee, which will in turn set up the Advocacy Commission. We have not laid down strict guidelines as to how this commission should operate, what sorts of people should be advocates, how they should be trained and so on, for the very reason that we want those people who have been there themselves to have input. I just wondered whether you had looked at section 15 of Bill 74, the listing of the people who should be on this advisory committee, and whether you would suggest any changes to that.

**Witness:** I have a problem with organizations because sometimes the organizations will pick a person who will

give a specific viewpoint. According to Health Watch, we have 1.5 million people who are mentally ill. Of those 1.5 million people, the stereotype of the not-too-bright or the violent is a very tiny portion. The people I have met first were professionals, academics and business people. I have met others since.

**Ms Carter:** But on this list we have eight categories. The last one, for example, is patients' rights organizations, organizations representing persons with disabilities. That is the kind of category we have here. I am just wondering how else you would set it up that would be more to your liking.

**Witness:** I think the people should not necessarily have to be chosen by the organization. I do not know exactly how; perhaps I could think it through and send it to you rather than wasting time. But I do believe the people who are receiving it should basically be in control. When we think of mentally ill people, I know professors etc, and I think those people are quite capable, far more capable than some of the people on the organizations.

I also doubt that some of the people who are criticizing patient advocates have ever met them. I think the most important qualification is the type of person. I think you should look first at the kind of person, and I think you know the qualifications. I have met only three. They are very special people and they are not antagonistic. I think they should have far more powers than they have now, because sometimes they are not allowed to have access to the information they need.

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**Mr Winninger:** I agree with you that there have been a number of psychiatric abuses in the past, and we have heard from some of the victims of those abuses. I also agree with you that the patient advocates have uncovered a lot of potential abuse and perhaps reduced the incidents that have gone on.

Where I do not agree with you, and perhaps you could clarify your position for me, is in this: I think I heard you say that there should be no civil commitment or treatment without consent. How do you deal with people who go around breaking windows or attacking people, not because they have any criminal intent but simply because they have a mental disorder?

**Witness:** I am sorry, I did not say simply "without consent." I said they should not be committed without consent unless they have had a chance to go before the law. A person can kill and be charged with manslaughter. He has recourse to the law, whereas the majority of mentally ill people or even people who are put into homes for the aged, sometimes, have not committed any crime, but the misdiagnosis is rampant. I am sorry but the abuses you are talking about still occur.

**Mr Winninger:** When you say "the law," you do acknowledge that there are boards of review in terms of civil commitment and consent to treatment?

**Witness:** But you see, if you commit a crime, you can go to the law before you are incarcerated, whereas if you are labelled, you can be put into a facility and then have to go before a board. I understand the doctor would be there,

and when you look at who the board consists of, it is difficult. How are you going to get a lawyer and all of these things, and if you have been given treatment, you may not be able to—

**Mr Winninger:** Would it not be better to deal with these people in a more therapeutic way than to lodge them in detention cells and bring them before judges who may not have the training or experience or background—

**Witness:** What do you consider therapeutic?

**Mr Winninger:** What do I consider therapeutic? Well, a hospital setting as opposed to a jail cell and a court of law.

**Witness:** What do they do in the hospital that is better? There are some things you do in psychiatric institutions or psychiatric wards that you cannot do in a jail, because it is against the law.

**Mr Winninger:** Okay, thank you.

**The Chair:** Thank you, Mr Winninger.

**Witness:** And if a person has committed a crime, perhaps he should—perhaps if you treat people better in a psychiatric facility—I would like to think about that one.

**The Chair:** Thank you. On behalf of the committee I would like to thank you for taking the time out this morning and coming and giving us your presentation.

**Witness:** Thank you for listening. I am sorry, could I say one important thing? There are chemical sensitivities. People talk about pollution all the time now. Many people are ill with this. I think proper medical workups should be done before you ever say a person is mentally ill or incapacitated in any way, because if you do not take into consideration nutrition and chemical sensitivities—medical professions accept that but certain people do not. I think people should have access to a proper evaluation, and not, you have a label, therefore you go, you get the same drugs, and for damage like tardive dyskinesia you get the same drug. What is the point?

**The Chair:** Thank you very much. We have to proceed, we have other witnesses waiting.

**Witness:** I am sorry. Thank you very much for listening, and please read the briefs.

**The Chair:** We will, thank you.

#### FAMILY COALITION PARTY

**The Chair:** I would like to call forward our next presenter from the Family Coalition Party. Good morning. You will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. Could you please identify yourself for the record and then proceed.

**Mr DiRocco:** My name is Louis DiRocco. I am the president of the Family Coalition Party. I am accompanied by Margaret Purcell, who collaborated with me on the brief. If you would like to follow, I will start on page 3, which is the preface.

The Family Coalition Party applauds the stated intent of the proposed legislation, to protect those who are vulnerable and incapacitated. However, contained therein are

obvious flaws which would increase the powers of an already powerful bureaucratic system and, in so doing, present additional burdens for those the proposed legislation purports to protect, their families and the medical profession.

The bills offer little protection and in fact would pose a threat to the security and life of individuals and would intrude on the rights and privacy of families while producing a quagmire of administrative, legal and moral problems. This brief addresses the deficiencies and dangers inherent in the proposed legislation.

1. Consent to treatment: Personal autonomy, a long-held principle of common law, guarantees competent patients the right to accept or reject treatment. The proposed legislation therefore provides no additional rights in this regard. On the contrary, it has a propensity, because of vagaries in definition, to place the patient in greater jeopardy. What average patient would consider it necessary to specify that he or she wishes to be fed? Yet looseness of terminology in Bill 109, section 1, could bring food and hydration under the mantle of treatment.

While Bill 109, particularly when joined to Bill 108, can erode the common law rights of adults or those most qualified to speak for them, it empowers minors with decision-making rights for which they are neither prepared nor qualified. A minor may therefore refuse to have his or her immunization injections on the ground that needles hurt, just as he or she may refuse dental care for the same reason. Minors may receive psychiatric care without parental knowledge or consent, just as they may be sterilized, contracepted or give consent to an abortion. Subsection 8(2) and subsection 10(7) apply to that.

Bill 108, clauses 47(7)(a) and 56(5)(a), together with Bill 109, section 15, paragraph 2, would allow sterilization to be performed on the grantor if it were considered necessary or therapeutic. This constitutes a gross violation of a person's rights and dignity. Sterilization is never medically necessary or therapeutic. In this case a person's body would be mutilated without his or her knowledge or consent.

Subsection 7(1) of Bill 109 provides for the reinstatement of power of consent, only to see such reinstatement overridden by subsection 7(2) which upholds the authority of the guardian of the person and the attorney for personal care appointed under Bill 108. The same applies to subsection 22(7) which reinstates the power of consent, only to have reinstatement denied by subsection 22(8). The implication under these subsections is that once a patient surrenders his or her right to consent, it is gone for ever.

Bill 109, subsection 5(3), allows for consent by implication. This begs the question, consent for what, to whom, and by whom. These provisions alone disqualify the proposed legislation as that which would protect vulnerable persons. They make the already vulnerable decidedly more so.

2. Role of the physician: There is the implication in Bill 109, section 4 and subsections 5(1) and 5(2), that physicians routinely overtreat patients, with or without their consent. This implication is divorced from reality. The overwhelming majority of physicians want and attempt to provide that which is best for their patients.

If the provisions contained in these bills become law, not only would the professional, ethical and moral integrity of physicians be under siege, but the wedge created by such an intrusion would diminish the trust a patient has for his or her doctor. This trust is not only conducive to but essential for efficient and necessary health care. Without faith in one's attending physician, a patient's potential for full recovery is jeopardized.

Where cure and recovery is not possible, the alleviation of the patient's suffering, implemented within the confines of medical ethics, becomes the physician's prime responsibility. Because of the advanced understanding of pain control, supplemented by the specialized care in palliative medicine and services found in the hospice movement, such an objective is distinctly attainable.

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3. Rights and role of the family: The government's responsibility is to support and protect society, not to replace the family, which is the basic unit of society. Yet this proposed legislation seeks to not only weaken the structure and authority of the family but to force vulnerable persons into the arms of the state.

The family, traditionally regarded as the unit which offers the most protection and support for one of its members, will see its desires, rights and responsibilities superseded by the considerable powers enjoyed by the advocate, the attorney for personal care and the public guardian and trustee.

With Bill 109, subsections 16(1) and (4), setting the order of precedence regarding those who may speak for the incapacitated, the family comes last. Having already introduced an element of mistrust between the patient and the attending physician, Bill 109 implies that the patient cannot trust his or her family.

Bill 74 effectively places the advocate in a position of power over the family. His or her power to arbitrarily override decisions made by the family further undermines the family's role and diminishes the special relationship which normally exists between family members.

While Bill 74, section 30, does not require that the advocate give information to the family of a vulnerable person, the once overzealous attitude towards privacy becomes extremely transient. For example, sections 17 to 19 allow broad powers of entry. The terms of subsection 21(1) are so vague that an advocate could, in the absence of adequate checks and balances, enter a person's house with little reason.

There should be the presumption that the family, who know the patient or vulnerable person best, will be the most reliable source of support and care. The role of government here is to assist. A breakdown in familial structure is a breakdown in society.

4. Living wills: The logical conclusion to Bill 108 is the introduction of living wills. The stated purpose of the living will is to allow competent persons to specify the treatment they wish to accept or decline should they become incompetent in the future. As a legal document, a living will undermines the discretion of the physician, forcing him to comply with directives which may be detrimental to the patient, just as it confines him in layers of

bureaucracy. It falsely implies that patients do not have the right to refuse treatment and reinforces the element of mistrust—mistrust of family and doctor.

In its practical application the living will is seriously flawed. A document signed today may have, given ongoing advances in medical science, little or no relevance two years later. Similarly, the attitudes of patients change. A person who signs a living will while in a depressed or apprehensive state may change his or her mind and see life as something definitely worth living.

How does a living will signed in Ottawa affect a patient unconscious in Fort Frances? To be effective, will it become another part of a file entrusted to the state? Will this document become another page in the already far-too-open book on individuals?

Wherever living will type of legislation has been introduced, the push for euthanasia legislation has rapidly followed. The presumption in favour of life is eroded.

5. The living will-euthanasia connection: It is essential that those dealing with proposed legislation on living wills and natural death be aware of not only the organizations promoting living wills but also the moral and social fallout following acceptance of such legislation.

Derek Humphry, past president and cofounder of the national Hemlock Society and past president of the World Federation of Right to Die Societies, advocates the use of living wills to achieve euthanasia. He says: "We have to go stage by stage, with the living will, with the power of attorney. We have to go stage by stage. Your side would call that 'the slippery slope.'"

The Iowa College of Law has drafted a Model Aid in Dying Act under the direction of Professors Sheldon Kurtz and Michael Saks. Professor Kurtz has directed other projects, such as the Model Human Reproductive Technologies and Surrogacy Act, which received serious consideration. The Model Aid in Dying Act is expected to be offered to legislatures across the US. It would allow parents of children under six years of age to request aid in dying for their children. Children six years old and over would be permitted to request death and, should parents disagree, allow a special aid in dying board to make the final decision.

Since Holland accepted a statute permitting living wills, evidence is mounting that euthanasia is administered to non-terminally ill patients. The Royal Dutch Medical Association has reached the point of advocating full active euthanasia, including the right of children to elect to die. The Dutch Medical Disciplinary Board, which may be considered the counterpart of the Canadian Medical Association, found a doctor guilty of breach of trust for declining to provide lethal drugs. Euthanasia has become so acceptable in Holland that every physician in the nation has been supplied by the Royal Dutch Pharmacists Association a 10-page pamphlet listing the most efficient ways to kill patients. It is now estimated in Holland that more people die by involuntary euthanasia—homicide—than by voluntary euthanasia. A recent government investigation has revealed that last year 15,205 Dutch patients were killed without their consent.

In California attempts were made in 1988 to amend the existing law. Speaking at the World Federation of Right to Die Societies convention in San Francisco, Robert Risley, coauthor of the Death Act and head of Americans Against Suffering, in speaking of the living will law said, "We must change the law ever so slightly." In speaking of death by starvation and dehydration he stated, "There is a better way," the proposed aid in dying: the lethal injection.

One year after California passed the nation's first living will law, Robert Duzon, administrator of the health care financing administration of the then Department of Health, Education and Welfare, suggested that living wills would be of major benefit to the nation's economy. Federally, the Patient Self-Determination Act, sponsored by Senators Danforth and Moynihan, requires health facilities or providers to ask if patients have a living will. Living wills are recommended as an ideal vehicle for trimming the federal budget. Also federally, Dr Otis Bowen, Secretary of Health and Human Services, when testifying before the Senate finance committee, stated that encouraging living wills was the only way to attack expenditures.

In May 1990, Hemlock's Washington state chapter and the Washington Citizens for Death With Dignity, Hemlock's political arm, implemented a signature campaign in support of Initiative 119, the death with dignity initiative, in attempts to amend the Natural Death Act, which concerns living wills, to include aid in dying or the lethal injection as an option for living wills.

In Ohio the living wills legislation, which has passed the Senate and is being debated in the lower House, has three major provisions: (1) expand the definition of "terminal condition" to include persistent vegetative state; (2) specify that food and liquids through a tube may be forgone in hopeless cases—these two are identical to the position of the Hemlock Society of Washington state; and (3) that even though a patient has not completed an advance testament or living will concerning the withdrawal of a particular life support system, it can be presumed that the patient wants it.

Former Colorado Governor Rich Lamm was reported as telling senior citizens, "You've got a duty to die and get out of the way."

6. Basic care: Food and water, while being vaguely categorized as medical treatment in Bill 109, section 1, and Bill 108, section 46, is a fundamental part of basic care. We recognize that when death is imminent, attempts to feed the patient will be futile, burdensome and hazardous for the patient. At this final stage of life common sense and decency dictate that the patient should be kept comfortable and free from pain. However, the withdrawal of food and hydration under other circumstances will bring about an agonizing death for the patient and contravenes section 226 of the Criminal Code.

The promoters of euthanasia consider denying this elementary care to the patient a very important step towards introducing the lethal injection, all in the name of mercy, all on the false premise that health care providers deliberately prolong the act of dying.

7. Cost containment: Governments continually call for the streamlining of health care costs. This proposed legis-

lation, if implemented, will magnify costs due to its bureaucracy. This government has already admitted that the estimated cost of administration will be between \$20 million and \$30 million annually. What will be sacrificed to pay for this unnecessary and fruitless project?

The present government shows no sign of being receptive to measures or incentives which would effectively cut costs while maintaining the integrity of the patient. Each year it spends millions of health care dollars on abortion—the deliberate termination of a pre-born child's life—going so far as to pay for the procedure, plus up to \$1,000 in administration costs for each abortion and transportation costs for the mother, all of this for a procedure which cures no illness, alleviates no symptoms and which has never, in Canadian parliamentary history, been designated a medical necessity.

In spite of this immoral use of taxpayers' money, financial support for families willing to take care of patients in their homes is lacking. Financial assistance for house modifications, adequate training, nursing care, relief for family members and education in basic procedures would efficiently streamline costs while allowing the patient to remain where he or she is most comfortable. For example, the initial cost of building an extra room with bathroom is \$25,000; nursing care on a daily basis, \$30,000 per annum; medication costs, \$12,000 per annum; transportation, \$1,200 per annum; total cost for the first year, \$68,200; total cost for subsequent years, \$43,200 per annum. The cost of maintaining the patient in chronic care hospital at \$500 per day is \$182,500 per annum; at \$1,000 per day the cost is \$365,000 per annum.

Add to this the estimated cost of administration, \$20 million to \$30 million, and it becomes abundantly clear that in terms of cost alone most chronic patients should, wherever possible, be cared for at home. Home care in terms of personal privacy and dignity cannot be compared, in most cases, to institutional care.

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8. Ambiguities: One of the disconcerting aspects of these bills rests in their propensity to be ambiguous. Here are three examples:

Vulnerable person: The definition of "vulnerable person" in Bill 74, section 2, is so vague that it could include almost anyone, thereby allowing an advocate to intrude indiscriminately in family life.

Capacity: One of the most glaring inconsistencies in the legislation is the absence of a provision to determine whether the grantor has the capacity to give power of attorney for personal care. If the grantor lacks capacity to make decisions regarding his or her personal care, how can he or she assign an attorney or name assessors who will assess his or her capacity?

Advocate or assessor: Another ambiguity is the role of the advocate and of the assessor. These two persons have considerable power and responsibility, yet nothing in the legislation requires that they have even minimal qualifications and training or defines the procedures and standards under which they would carry out their responsibilities.

9. Conclusion: This legislation sets up an impersonal, bureaucratic system which would permit certain persons to

control the lives of vulnerable people or even determine whether they live or die. These persons would legally make decisions over which vulnerable, incapable people or their families have no control whatsoever.

The proposed legislation has the capacity to establish another level of impersonal, state-controlled bureaucracy which will strip individuals of their human, social and moral rights. By denying the family the right to make ethical decisions, it allows the state to make life and death decisions on a quality of life and cost containment basis. This is a proven technique in the dehumanizing and destruction of society well documented by the events immediately preceding the Second World War. It is doubtful that a once noble culture will ever totally recover from the assault on and the eventual surrender of its humanity.

The Family Coalition Party opposed Bills 131 and 132, just as it opposed Bills 7 and 8. It categorically opposes these bills, which would not be made acceptable by amendments. It calls for the immediate, total withdrawal of this proposed legislation and calls upon the government to return to its role of servant, not master, of the people. Thank you.

**Mr Poirier:** I presume, from reading your brief, that you are against the principle of, for example, the current age for young people as per the bill being 16 to be able to have access to medical treatment without parental consent. Do I read that correctly?

**Mr DiRocco:** As a general rule, yes. Do you want me to comment further?

**Mr Poirier:** Under no circumstances would young people under 16 have access to medical information or help or whatever it is without their parents' knowledge.

**Mr DiRocco:** The danger here is that minors could have access to the things we mentioned without their parents even knowing about it. There is that possibility.

**Mr Poirier:** Right, but do you oppose their capability of giving consent under the age of 16 to any treatment or to specific ones?

**Mr DiRocco:** Certainly the ones we mentioned. Do you have further comments?

**Mrs Purcell:** I think that at the age of 16 a person is not qualified emotionally or otherwise to make certain decisions, so in that regard the person should be accessible to support and counsel from those whom he or she should most trust: the parents and members of the family.

**Mr Poirier:** How about if a young person under 16 wanted to have access to contraception?

**Mrs Purcell:** I would be opposed under any circumstances for a number of reasons. For one thing, I do not think contraception should be the means to letting boys use girls as sexual garbage dumps. I also have concerns about the side-effects of contraception on young and more mature people, so I would certainly be opposed to contraception under any circumstances, but under circumstances where the guardians of the young person are not informed even more so.

**Mr Poirier:** How about access to condoms for young people under 16?

**Mrs Purcell:** I think that when we make condoms accessible to anybody under 16 or otherwise, we are playing Russian roulette with another person's life. The manufacturers of condoms themselves admit that the condoms have between a 17% and a 30% failure rate. You would not let your child drive a car that had a 17% or 30% failure rate. Similarly, I would be absolutely opposed to the distribution of condoms particularly to a minor and particularly without parental knowledge.

**Mr Poirier:** How would you protect young people under 16 from sexually transmitted diseases and AIDS?

**Mrs Purcell:** The only proven protection against sexually transmitted diseases is a monogamous relationship, desirably within the confines of marriage. I would hope that once again by brainwashing we would not force upon our young people an emotional relationship for which they are not prepared. Any relationship, to survive, must have commitment. That means responsibility as well as rights. I believe this does not come with a loose type of relationship devoid of commitment.

**Mr Sterling:** Given that the present law recognizes a living will, do you not think it is in the vulnerable person's interests to define in legislation the limits of a living will, to define whether that person is capable of making a living will and to define how a health care provider should interpret that living will? Do you not think it is better to confine? In effect, what this legislation does is confine the use of a living will rather than open it up.

**Mrs Purcell:** I do not see that the living will really serves any purpose that cannot be served without the use of the living will. One of my primary objections is that it is undermining and even usurping the discretion of the attending physician, which brings me back to an earlier point that we seem to be promoting the philosophy that patients are overtreated with or without their consent. I myself come from a nursing background. It just simply does not happen. We do not have the facilities or the desire to routinely and seriously overtreat patients. So I would be concerned about removing the power of discretion from the physician. Even though their track record with regard to abortion is absolutely abysmal, apart from that, I believe the average physician truly has the best interests of his or her patient at heart.

**Mr Sterling:** You did not answer my question though, with respect, but I have come to the conclusion that you would rather give the health care provider the decision over life and death decisions than the patients themselves.

**Mrs Purcell:** We are talking about incompetent patients here, because that is the purpose of the living will, which brings me back to another point. I believe consultation should be made with those who know the patient best and care for the patient best. That is normally the family.

**Mr Sterling:** But there is not always a family.

**Mrs Purcell:** That is why I said normally. In other circumstances, you might want to consult another person who knows the patient well. It might be a friend or an associate etc. What I am concerned about is the erosion of

the rights and the input and consultation by those who should know the patient best.

**Mr Sterling:** Could I go back to my original question that a living will is legal in Canada and in Ontario at the present time? How can you argue against legislation which, in effect, legitimizes the living will in that it requires certain witnesses, it requires certain assessment of the individual as to his or her capacity to make that living will? How can you argue against legislation which, in effect, limits living wills rather than expands living wills as they presently exist in law?

**Mrs Purcell:** Well, you are inferring, first of all, that what is legal is right or good, and I would have to dispute that very strenuously. Regardless of whether or not it happens to be legal, I do not think it is good. I am saying that a living will does not give to a person, on the average, something that he or she does not always have.

**Mr DiRocco:** Already have.

**Mrs Purcell:** Already have. I am sorry.

**Mr DiRocco:** I would like to add a couple of points to that. The document the patient signs at the time he signs it may not be implemented in the way he projected that. Two or three years later the situation may be changed and the interpretation given to the living will by the person attending may be quite different from what the person intended when he or she signed the living will. So that is another reason we would not be in favour of such a document. The actual patient may have changed his mind about it, about his particular treatment or what he wrote in the living will, and he was not able to notify his physician or may even have forgotten to notify his physician. There are all kinds of situations. You cannot possibly account for every possible circumstance in a living will.

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**Mr Sterling:** I agree. Your paragraph in your conclusion says, "The legislation sets up an impersonal, bureaucratic system which would permit certain persons to control the lives of vulnerable people or even determine whether they live or die."

But what happens now, sir? Now certain people make those life and death decisions. The purpose of a living will and a power of attorney, as put forth by myself in my private member's bill and I believe embodied in this legislation, is to take away the decision from people now who are determining life and death decisions over people in Ontario and give it back to the person who is living or is going to live or is going to die. In other words, respect that vulnerable person's wishes. How can you argue against such a basic, basic principle?

**Mr DiRocco:** Well, we just have.

**Mr Wessenger:** It seems to me that what you are telling us is that you do not agree with the existing principles of common law that a competent patient has the right to accept or reject treatment if that competent patient happens to be a minor. Is that what you are saying, that you do not really believe a child who is capable of making a decision with respect to his own treatment can make that decision on his own?

**Mr DiRocco:** Normally you would consult the parents of such a child. What we are concerned about is a child, let us say it is a teenager—and our party, you know very well, is concerned about abortion, for example—could go to a doctor—the parents would not even know that their daughter was pregnant—and could arrange an abortion. They would not even find out about it. That is possible under this legislation. Do you not think that the parents should at least know about such a situation?

Let's say that their daughter or son is depressed. Do you not think that they would want to know whether their son or daughter is depressed? Under the circumstances, the doctor would call in an advocate; the doctor would not call the parents, he would call an advocate under this legislation.

**Mr Wessenger:** Sorry, you are quite incorrect with respect to the matter of the advocate. The way the situation now works with a minor child, a minor child goes to the medical practitioner, the medical practitioner now determines whether the minor child has the capability of making the decision. If the medical practitioner or health practitioner decides that the child does have that capability, then the practitioner takes the instructions from the child and gives the treatment. That is the existing law, and Bill 109 in no way changes that principle; it merely tries to clarify the principle.

**Mrs Purcell:** I do not think that it has clarified it sufficiently. I have shown these bills to several people, all of whom I would regard as well-educated people, all of whom I would regard as being those who would seek the truth, and all of those people have come up with concerns regarding the ambiguities and the lack of clarity in the bills in all those regards. When there is lack of clarity with one thing, it begs the question of what else is not being made clear to the Ontario public.

**Mr Wessenger:** The other thing I would just like to clarify is section 15 provides that, "Nothing in this act authorizes a health practitioner to perform...sterilization that is not medically necessary for the protection of the person's health." So it seems to me that your comments with respect to the question of sterilization are incorrect.

**Mrs Purcell:** Absolutely not, because who decides what is medically necessary? How would sterilization, within itself, possibly be construed as medically necessary or therapeutic?

**Mr Wessenger:** I certainly could think of circumstances where a pregnancy could result in the death of the individual.

**Mrs Purcell:** Then you are looking at a pregnancy; you are not looking at the actual sterilization. I dispute that a death is going to be the result of a pregnancy. A 10-year study of the largest obstetrical hospital in the British Isles has failed to document one single case where a person has died simply because of a pregnancy.

**Mr Wessenger:** I would also like to point out some inaccuracies in your brief with respect to the cost of institutional care. First of all, chronic care costs are generally \$200 a day per patient, not \$500 as indicated. Second, with nursing home care, the costs are approximately \$25,000 per year in an institution, although I agree with you that it

is certainly beneficial to keep people in their own home and have the family look after them.

**Mrs Purcell:** You should speak to the government agencies. I got my information from them.

**Mr Winner:** Just in terms of Bill 108, under section 4, living wills, you state that: "In its practical application the living will is seriously flawed. A document signed today may have, given ongoing advances in medical science, little or no relevance two years later." That is precisely why you see subsection 63(3) in Bill 108, which deals with more recently expressed wishes, read together with clause 28(1)(c), where there are more recent wishes expressed in Bill 109. Those wishes and instructions can be taken into account, particularly in regard to advancements in medical technology and the kind of treatment benefits that might flow from that.

**Mrs Purcell:** By an unconscious patient perhaps?

**Mr Winner:** Yes, and the only other quick point is this: You question the capacity of someone who executes a power of attorney for personal care. We have tightened up the requirements for powers of attorney. You require two witnesses and those witnesses attest to the capacity of the person who executed the power of attorney for personal care. If you wanted to question capacity, you could question the capacity probably of every will that has ever been executed, because you have similar provisions, two witnesses testifying for the capacity of the testator. I have some difficulty buying into that argument that people may not have capacity, simply because we have safeguards in place to ensure that the person who executes the power of attorney does display capacity.

**Mrs Purcell:** We are just asking that they be made clear—well, saying that they should have been made clear. We are not asking that they be made clear because we would like to see all the bills withdrawn.

**The Chair:** Mrs Purcell and Mr DiRocco, on behalf of this committee I would like to thank you for taking the time out this morning and coming and giving us your presentation.

**Mr DiRocco:** You are welcome.

**Mrs Purcell:** I want to make one comment before I go. I got my figures from government agencies.

**The Chair:** Thank you very much.

#### KERRY'S PLACE

**The Chair:** I would like to call forward our next presenters, from Kerry's Place. Good morning. Just a reminder you will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses.

**Ms Newman:** We are going to do our best.

**The Chair:** As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Ms Newman:** I would be glad to. My name is Elaine Newman. I am a lawyer. I am a full-time vice-chair on the

Workers' Compensation Appeals Tribunal, but I am here today in my capacity as a member of the board of Kerry's Place. With me are Mr Howard Weinroth, chairman of the board, and Mr Roland Beauregard, second vice-chair. You had some other names on the schedule of members of our delegation, but unfortunately, due to illness, we are limited to the three of us this morning.

I would like to take a few moments, if I may, to make some submissions to you and then invite you to ask questions, which Mr Weinroth and Mr Beauregard may be better able to answer than I. I would like to take a few moments to explain to you what Kerry's Place is. I would like then to take a few minutes to explain to you the nature of the disability we are concerned with this morning and to explain to you what, in our estimation, the impact of the proposed consent to treatment legislation would be on the population we are concerned about. We are here this morning only to address some narrow areas of concern that pertain specifically to the Consent to Treatment Act.

Kerry's Place was founded in 1974 by a group of concerned parents and professionals familiar with autism. It was founded for the purpose of providing services to people with autism, and that includes residential services, educational, vocational and social services. The organization has grown over the years, and now it includes six residential centres and a network of community services.

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Kerry's Place represents a very small population in comparison to that which you are accustomed to hearing about in these proceedings. We are here to talk to you about the concerns of our population, and our population is only approximately 100 people with autism, although we do not represent all of the people in the province of Ontario with autism, only those who are affiliated in some way with Kerry's Place. So this organization provides services to a small population of children and adults who have autism. Kerry's Place operates according to a specific philosophy. I have summarized that for you at the first page of our brief submission. If I may, I am going to quote very briefly:

"Kerry's Place views every client first of all as a person, not as an autistic person, but as a person with autism. Each client has likes, dislikes, and the same rights to independence and the pursuit of happiness that all other individuals have.

"Kerry's Place strives to help each individual reach the highest level of independence in a lifestyle that they are able to achieve. Kerry's Place will advocate on behalf of its clients for whatever provisions are necessary to make this achievement possible."

But this is an organization in which all involved, at the board level, at the service provision level, are very much devoted to the notion that each individual is to be respected, that his or her abilities are to be enhanced to the greatest degree possible.

What we wish to do this morning is to articulate in the context of this particular and special population some of the practical implications which the proposed consent to treatment legislation will have. But in order to make that position clear, it will be necessary for us to explain the

nature of this rather peculiar disability. This is not easy, because not a great deal is known about autism. Not a great deal is known about the cause or about the exact nature of the disability. We do know that it is primarily a communication disability. Although often people with autism also have other problems or disabilities, this is not universally so.

It is important for the members of the committee to understand that autism is not synonymous with developmental disability. Within the Kerry's Place population, therefore, there are children and there are adults who are bright, intelligent, capable and insightful people. Their problem, however, is that they cannot communicate. Many aspects of their appearance, aspects of their behaviour, may cause them to appear to be developmentally disabled, so autism is easily mistaken for a developmental disability. This is true not only in the general population, in the general public; this is also true among physicians, it is true among psychiatrists and it is true among neurologists. Autism is difficult to identify, and it is difficult to diagnose. Therefore, it is common for people with autism to mistakenly be identified as people with a developmental disability.

Within Kerry's Place there are people who suffer from varying degrees of developmental disability, and there are people in this population who would lack the mental capability to provide consent to treatment. But within this population there are also some very high-functioning individuals whose problem is only that they will not be able to communicate and they will not be able to convince a health practitioner that they are mentally capable individuals.

Let me explain one other aspect of autism and about communication for people with autism. It is something with which you may have become familiar recently. This is a mechanism of communication called facilitated communication. You may have read about it in the *Toronto Star*; you may have seen the 5th Estate program or The Journal article or the 20/20 program on facilitated communication. It is a very recent development and, again, very little is known about how or why it actually works, but a person who has autism may be able to communicate using this recently developed process called facilitated communication.

With the help of another person, a facilitator, the individual may be able to point to letters on a board or may actually be able to type letters into a keyboard and spell out words. The other person, the facilitator, is necessary to sit beside the individual with autism to guide his hand and to exert a pressure which acts as a counterpressure. That appears to enable the person with autism to have greater muscular control. So another individual is necessary, as well as the mechanism, either the letter board or the typing equipment.

Through that very slow and very painstaking process, some people who have autism have recently, for the first time in their lives, been able to communicate. Within the past year, and for some the past two years, for the first time in their lives they are able to communicate with the rest of us and they are able to tell us, through this means of spelling out words, their wishes, their preferences, their desires, their thoughts and their feelings.

As a result of this quite remarkable and recent development, we have learned that people who are in this population have much more high-functioning abilities and much greater intellectual sophistication than we ever thought they had before, because now, for the first time, they are able to communicate. It is an astonishing process. It is one we do not understand. It is one that health care professionals do not completely understand. But we do know that for the first time people who suffer from this very challenging disability are able to communicate. What comes with this is a very new and a very fragile self-esteem. This is very exciting.

For the first time some of the Kerry's Place population are able to communicate what it is they are thinking and feeling and what it is they want, and for the first time their wishes are being respected. That is a very exciting process. This is a process which the Kerry's Place staff and board and families are devoted to enhancing. They are devoted to enhancing the sense of dignity and self-esteem that comes from being now able to communicate. So we have a very unusual population. We have a population where some of our members very remarkably have recently developed the ability to communicate and a fresh, burgeoning sense of self-esteem.

What does all of this have to do with Bill 109? We have sat down and tried to project what some of the practical implications of Bill 109 will be for our clients and of course for our staff and for the families who are involved. We would like to share those with you.

Our concerns stem from the conclusion that Bill 109 as presently framed is going to make routine health services virtually inaccessible to part of our population. That is an astonishing discovery, because by and large Kerry's Place encourages the legislative initiative that is here under discussion: the concern for vulnerable people, the importance of seeking the consent of the individual and making him or her an involved player. These are theories that we agree with entirely, that we strive to achieve in our own work. But because of the way the legislation is structured, that is not going to be the effect this legislation will have on this population. Quite the reverse is true. What is going to happen here is that routine health services are simply not going to be accessible. Let me explain why that is.

Let's contemplate a mentally capable adult, a 19-year-old person with autism who is very bright and very capable and who knows exactly why he or she is going to the doctor but is not able to communicate with the doctor. This is an individual who may mistakenly look mentally incapable. He or she may look developmentally disabled. They are not going to be able to convince the health practitioner that they are capable. In the unlikely event that a facilitator is available to go with the person to the doctor, it is extremely unlikely that even the most well-intended and well-motivated health practitioner is going to have the time to sit down with the person and embark on a facilitated interview.

I conducted an interview with Mr Weinroth on Sunday afternoon. It took approximately an hour and a half for us to go over some basic material. In the course of that interview, I explained to him the nature of this legislative initiative and

learned of his responses, and he shared my concerns. I was impressed, certainly, by the degree of sophistication of the responses, but I was more practically impressed with the amount of time that it took him to communicate with me. It is a very slow and painstaking process.

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Now what is going to happen? The individual will go to the doctor, probably with a parent or a staff person from Kerry's Place. The doctor is not going to be convinced the individual has mental capability and that doctor is not going to be able to provide service. He simply will not be able to. He will not be comfortable doing it, and in fact this law will preclude him from doing it without triggering a complex process of putting the individual on notice that he feels the individual is not capable, calling in an advocate and then looking for substituted decision-making. That is an extraordinarily complex route to have to go to have a routine medical examination performed, but that would be the application of Bill 109 to this population.

The other pieces of legislation you are contemplating in conjunction provide an answer for part of our population and part of the disabled population in the province, and the answer is, if all that is too complicated, the route is to go to a court and get an order for personal guardianship.

First of all, a 19-year-old mentally capable individual who cannot communicate does not have that option. If the parent was to go to court and seek an order to become the personal guardian for the purpose of communicating the individual's wishes, that order is not available to him because the person we are talking about is indeed mentally capable.

For those who are less mentally capable—and as I have said, they are included in our population in varying degrees—our concern is the same as that which you have heard from the Canadian Association for Community Living and many of the other associations: that a global capability determination and personal guardianship appointment is an affront to dignity which is too comprehensive for the kind of problem these individuals may face.

I must add a specific concern with respect to part of the Kerry's Place population that we are concerned about. Those are the mentally capable individuals who have only recently begun to sense self-esteem. These people are going to face regular, routine challenges to their mental capability every time they have to go to a doctor, every time they go to a chiropractor, every time they seek routine health services. I suggest to you for someone with a brand-new, fragile sense of self-esteem, repeated routine challenges to mental capability are going to be very difficult things to face. It is going to operate against the effort of the Kerry's Place organization to enhance self-esteem. We will have taken an enormous step forward in terms of communication and individual dignity, and every time the individual goes to seek health services, he is going to be challenged with a new investigation into his mental capability, an extraordinary challenge for this unusual population.

Do we have an answer for you? Do we have a quick fix or a quick amendment which will make your jobs easier? No, I regret we do not. We recognize that our submission

is in an unusual context, and it does pertain to a relatively small population. However, we want you to understand that notwithstanding the lack of clarity that we operate within at the present time, the lack of clarity and the lack of statutory intervention right now enables this particular population to get health services. This is one of the unusual circumstances in which the foggy legal environment is one which works in favour of the population. Our people have no trouble getting top-notch health care.

This is an environment which operates in the context of respect for the individual. To the greatest extent possible, the individual's wishes are sought and are reflected in the decision. Our fear here is that the cure is going to be detrimental and it is going to be worse than the evil which we are seeking as a society to address.

Those are our submissions. If you have questions, as I have suggested, it may be that Mr Beauregard or Mr Weinroth would be better able to answer than I, and we thank you for your attention.

**The Chair:** Thank you. Each caucus has three minutes.

**Mrs Sullivan:** I think if these hearings have done little else, they have certainly brought to the attention of the members of this committee the varying scopes and broad base of differences in our population. I think for that purpose it has been very useful that you have been here.

We are dealing with legislation which is very broad-based, which is being designed to apply to all scenarios and is all-encompassing, and I think the point you make about the requirement of Bill 109 for repetitive capacity assessments—which would not only be limited, interestingly enough, to the autistic patient. There are many other patients whose organizations and agencies and support groups have been before us who have indicated that this same kind of thing would affect them and would also have an effect on the self-esteem of the people involved.

A number of organizations have come before the committee—and they include the Ontario Medical Association, the Friends of Schizophrenics, the Nurses' Association of Ontario, the College of Physicians and Surgeons, the College of Nurses of Ontario, the association for residential care and the Metropolitan Hospital Council—and indicated that they feel the best way to proceed with this legislation is indeed to withdraw it, to submit the government amendments and let people have a view of what those amendments are and provide time for an analysis of those amendments and possibly additional public hearings before proceeding any further. That is a view my party supports, because we are very concerned about some of the very issues you have raised, and we feel that is the only rational method of proceeding, other than abandoning the whole process. I wonder if you would support that kind of step so that if there is going to be a statutory clarification of common law, that would be the appropriate approach.

**Ms Newman:** Yes. In our view the initiative, as I have said, is one which is very important. The members of this delegation have been involved with different segments of the community of disabled people in this province for a very long time. We appreciate that the complexities are

vast; the array of problems, the variety of problems, is extraordinary. We learn more about disability every year.

This initiative is one which in context has been rapid. Because of the importance of the issue, because of the fear of abuse, it is one which may have been too rapid, and we certainly support an initiative which would not lose sight of the importance of the issues but would enable greater thought and greater clarity to be brought to the process.

**Mr Poirier:** Obviously you may claim that you are a small number of people, but the fact is, regardless of how many people there are, I am glad you came forward and explained how in the practical application this is going to cause more problems than anything else.

I am a Capricorn and a very realistic type of person. How would a health care giver be able to know, in all good faith, that the person in front of him or her does have full competency? How do you go about doing that, and is it common for a person with autism to come forward all by himself or herself to the health provider? Is that common? I am trying to put myself in the shoes of that health care provider. How would I know?

**Ms Newman:** Yes, it is an important question. Perhaps Mr Weinroth or Mr Beauregard can explain the kind of comfort level that has been achieved among the clients of Kerry's Place, the service providers and families to offer that kind of confidence to the health care provider.

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**Mr Weinroth:** Prior to the arrival of the individual with autism at the health care practitioner, whether it be a doctor, chiropractor, dentist etc, it has been explained to the individual the reason for the up-and-coming visit, what could entail during the visit. If contact with parents is done on a regular basis, parents are certainly informed. With the tremendous excitement generated by facilitated communication, a facilitator will accompany the individual to the health care practitioner and the whole process will be further explained onsite.

What we have always done is maintain a very close and healthy relationship between the parents, where possible, and the care giver. Ours is a very caring staff. Most of the time the individual is accompanied by a staff member. The agency has on file regular visitations with various health care practitioners. They also involve the individual with autism in the planning of care. Even before facilitated communication, what we tried to do was be a holistic organization where we involve the parents and, where possible, the guardian of the individual for total care, not just medical care. We have always tried to maintain this relationship. We have always tried to maintain consent to our plan of care. We always try to incorporate in the plan of care the wishes of all concerned, and now more so with facilitated communication the consent of individuals is sought and appreciated, incorporating their wishes. It is a very complicated process. When the individual arrives at the doorstep of the health care practitioner there has been much planning and preparation.

**Mr J. Wilson:** Thank you very much for your presentation. It is always interesting to follow the individuals as we do here in rotation. I did not know Mr Poirier, for

instance, was a Capricorn. I am just wondering if you have had opportunity to compare notes with Nancy Reagan on how horoscopes are involved in decision-making.

None the less, we too as a caucus have expressed many of the concerns you have brought forward in your brief, as have many other groups. Briefly, to play devil's advocate, you make a point in your brief about, "Capacity determination procedures invite applications for personal guardianship." I read into it that this could be very intrusive to people living with autism. You go on to say it would cover many cases; in fact "all purposes" is your language. I am wondering, though, with the new communication techniques you brought to our attention—and I think many of us saw the TV programming on this—will the courts not take into account the wishes of the person with autism?

**Ms Newman:** Mr Wilson, one of our preliminary problems is that at this point we have some concern about whether facilitated communication would be an acceptable method of interpretation in courts of law. Facilitated communication is difficult because another individual is involved in the process and there has been some question raised about the degree to which the facilitator inputs into the answers of the individual. We expect it would be some time before we are able to establish facilitated communication as a recognized form of interpretation. It is one that has people puzzled and concerned.

Having said that, it is certainly our hope that the wishes of the individual would be taken into account by the court, but there again it is a catch-22 situation. If a judge is looking at an application for personal guardianship, he or she has to make a finding with respect to mental capability. On the one hand, many of these people are mentally capable. The problem is communication. For those individuals, the court cannot make a finding that there is a lack of capability and cannot appoint a personal guardian. We would have a very disabled person who cannot communicate but who has inside of himself privately a great deal of mental capability. That person is going to be in a difficult position.

For those with less mental capability, the position is very much the same as that which you have heard with respect to people who suffer from slight degrees of developmental disability or fluctuating psychiatric conditions. Determination of mental capability for one purpose may not hit the mark for the others.

**Mr J. Wilson:** Thank you. Your comments were very helpful.

**Mr Fletcher:** Thank you for your presentation. I want to relate a bit of a story. It is about my ex-doctor who developed MS. As the disease progressed, he had to give up his practice. He was in a wheelchair. We were talking one day and he mentioned how he has to relearn and rethink everything, because of his disability, in how to treat disabled people. He never realized how to treat disabled people until he actually became disabled.

I noticed, as I was reading through your brief, you talk about practitioners who will not be able to communicate with people or understand people. It appears to me that the education, as far as the vulnerable person is concerned, is

shifted to the practitioners, the health care providers, who need to be educated perhaps on how to communicate and how to deal with people with disabilities.

The other part of it is that you say people are going to their practitioners and their health care providers on a routine basis for routine medical care. After a while my doctor would pull out the file; he knew who I was and he knew the treatment. I think the same thing would happen after a while. Once a person is going on a routine basis to a doctor, the doctor gets to know things about each patient and how to communicate with him or her. It may be a long process, yes, but I think in the end the individual's right to treatment should be respected by all doctors and by all health care practitioners. If they are willing to communicate, then that in itself should be the first step.

I do not see where the bill would get in the way if people can communicate, if the practitioner and the health care providers are performing their functions in the right way and if they respect their patients. Maybe part of the problem is that the medical association should be educating doctors in that way, and it is not happening. There are other things that get involved with this piece of legislation. I do not know if that is a question. Maybe it is more a comment than anything else.

**Mr Weinroth:** I am wondering if the letter of the law may tend to discourage doctors from looking favourably on patients who have been in their care for a long time and who do understand the disability and do share concerns. The law itself, as it is currently written, does not require the practitioner to presuppose or to seek mental competency on the part of the patient, even though he has known the individual for a long time. Would that not be enough of a scare tactic, a threat, on the part of the doctor to override his responsibility to the patient?

**Mr Fletcher:** Perhaps I am a little old-fashioned, but I still do hold health care practitioners and doctors in high esteem. I cannot see them using a law to the detriment of a patient if they know the patient and they have worked with the patient. Maybe it is naïveté on my part that doctors are that way.

**Ms Newman:** It may be, Mr Fletcher, that certain members of this population will have long-standing relationships with physicians and they will not face these difficulties. It may well be that some of them will be able to create in their physicians sufficient confidence in their mental capability to make their repeated routine challenges into mental capability unnecessary. That is something we cannot count on.

Certainly there is enough fluctuation in the medical community that our population, like any other, from time to time has to face a new medical practitioner: the doctor is out of the office and another doctor is in the office taking care of his or her patients; they are on vacation and a locum is in taking care of the patients; a new staff member comes in, or the clinics trade. The doctors trade patients and share patients and work cooperatively, so the individual relationships cannot be counted on as much as perhaps they used to be.

In this population as well, there is a need for access to a variety of different medical services. Chiropractic medical services are included in the definition for these purposes, neurological services, sometimes psychiatric. There is no community of medical practitioners with specialization in this area that this population repeatedly turns to. It is not as though we are going to the one specialist in the field in the province who has the facility in the area. It is necessary for our population to turn to the general population of physicians across the province.

I will add that although Kerry's Place represents only 100 people with autism, there have been estimates that there are as many as 10,000 people with autism, children and adults, in the province of Ontario, spread out all over the province, having access to the general medical population as well.

**Mr Fletcher:** Let me just say thank you for your presentation. If I were incapacitated, I would like to have a place like Kerry's Place to advocate on my behalf.

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**Mr Malkowski:** Thank you for your presentation. Personally, I have had the opportunity to work with children and adults who have autism, and I would agree with what you say. There are different needs within that population, some who are high-functioning and some who are no different from the general population. All it is, is communication needs.

People who have autism could use the computer as a communication facilitator; they could even use sign language because they have an opportunity to express themselves in a way that is not based in research yet. There are many deaf people who would prefer to use sign language interpreters to communicate with doctors because they feel more comfortable, but the doctors do not feel comfortable using the interpreters. Perhaps the medical professions would not feel comfortable with facilitators, but if they become familiar with the person and familiar with the environment and look at what is best for the person, then they would become more comfortable. So I would like to ask you this, specific to consent to treatment: If we look at the mode of communication or the provision of communication services, doctors perhaps would be more accepting of that variety of modes of communication. Do you feel they would be more willing to accept facilitated communication?

**Mr Beauregard:** It is not so much a question of mode of communication. Autism seems to be a disability that affects initiation of communication. That is where facilitation comes in. There is something that has to do with the backward pressure that allows an individual with autism to initiate an appropriate communication or at least the type of communication or spelling out of letters that he wants. We have used various modes of communication in the past. With various people with autism, various methods seem to work. What we have experienced in the last year is a quantum leap with some people with autism using facilitated communication.

Doctors—bringing us right back to physicians now and other health care specialists or health care givers who have a relationship with some of these people—have an image

or a certain level of understanding of them. They may believe they are developmentally disabled, and we are finding now that some of them have insight and knowledge that is extremely surprising even to parents, as well as to the care givers at Kerry's Place.

What is particularly astounding is that some of these people with autism have shown us areas of knowledge that are surprising because they have had virtually no education. They have had basic life skills education, but they have had no academic education. When we probe we find that much of their education they have absorbed from their environment, including Sesame Street and other areas. Some of them are coming up with social judgements which are far beyond anything we would have expected them to know or understand. Some of them are calculating the hypotenuse of a triangle when some of the parents did not know what the hypotenuse was. So this whole question of communication is now opening up issues that we have raised today.

**The Chair:** Ms Newman, Mr Weinroth, Mr Beauregard, on behalf of this committee I would like to thank you for taking time out today to come and give us your presentation.

#### COMMISSION OF INQUIRY INTO UNREGULATED RESIDENTIAL ACCOMMODATION

**The Chair:** I would like to call forward our next presenter, from the Commission of Inquiry into Unregulated Residential Accommodation. Good morning. Just a reminder: You will be allowed a half-hour for your presentation. The committee would appreciate it if you would try to keep your remarks to about 15 minutes to allow time for questions and comments. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Dr Lightman:** My name is Ernie Lightman. I am the commissioner for the inquiry into unregulated residential accommodation. I would like to thank the Chair and the members of the committee for giving me the opportunity to come and talk with you for a few moments this morning.

The focus of my comments will deal with the Advocacy Act, Bill 74, and why I feel this bill is essential not only in the context of the work I have been doing with the commission of inquiry, but even more generally as a crucial support for the new approach to the welfare state, if I can call it that, that we will be entering into through the 1990s, a welfare state or a welfare society, as I prefer to call it, that is going to be governed by economic constraint and fiscal crisis. I might just add that my professional training is in economics, that my PhD is in economics, and that the fiscal issues have been very much in my mind through the last year or so while I have been doing this inquiry.

I would first like to talk about the context of the inquiry because I think this gives me the context for the comments. In November 1990 a man named Joe Kendall died in hospital after being assaulted by another resident at a place called Cedar Glen boardinghome. Cedar Glen was an unregulated boardinghome near Orillia, Ontario. Mr Kendall had been placed there by the Queen Street Mental

Health Centre. There was a coroner's inquest after Mr Kendall's death. It was the longest inquest in Canadian history. It lasted 61 days and it came out with some 80-plus recommendations. Key among these recommendations was that the Premier should appoint a commission to inquire into unregulated accommodation. Two days later my appointment was announced in the Legislature by the Honourable Elaine Ziemba.

The commission began its work January 1, 1991, and the report is now essentially complete. We are in the final copy-editing, worrying about the semicolons and the commas, and we are very anxious to be done with that. The report will be available after production; production, I am told, takes a couple of months.

During the course of our work we released a discussion paper last March in which we set out some of the parameters and some of the boundaries for our inquiry. We held public consultations in six or seven cities around the province. We received 240 written submissions and we met with all the affected interest groups, some of them several times.

For our purposes, "unregulated accommodation" means accommodation that is not licensed, not inspected by the province of Ontario, accommodation in which there are no standards that are set by the province and where there is obviously no enforcement. The only exception is that certain provisions of the fire code, public health and the building code apply universally, and they would apply. But there are no particular government protections for the vulnerable adults who live in this type of accommodation.

#### 1200

There are three major population groups: There are persons with psychiatric histories, there are persons with developmental disabilities and there are the frail elderly. Our mandate is limited to adults. Part of our task was to come up with a number, a population count, and of course I cannot tell you that today, but we do have a number.

During the course of the process, for the last 14 months, we have seen a lot of different types of accommodations that are offered within this broad framework. The accommodations include luxury retirement homes, where the quality of care, accommodation and services is absolutely exemplary, and range all the way to the other end, which is accommodation that is truly appalling. I have visited and seen some of these settings, and I am ashamed to acknowledge that these exist in Ontario in 1992.

Through the course of the inquiry we received telephone calls every now and then. We should have kept track of how often they came. We received telephone calls sometimes from MPPs' offices or their staff, sometimes from the press, talking about another "horror story" that had been uncovered: an old person who had been left in the bath too long and scalded, ex-psychiatric patients who were tossed out of their accommodations and left to spend the night on the street because they crossed the operator, persons with developmental disabilities who really have nowhere to live.

Unfortunately the bad news is that we were not able to offer these people any help. In certain cases the Criminal Code may be operative, but a Criminal Code test, as I am

sure you know, is a very rigorous one. During the last several months there was in fact the first conviction under the Criminal Code at a rest home. I use the words "rest home" as a generic label for all this type of accommodation. This was the first time a Criminal Code prosecution had been successfully pursued.

The commission was faced, first of all, with defining or identifying a range of options, and then with that range of options recommending a direction to the provincial government. These options really ranged from doing nothing to doing as much as we could. Doing nothing basically would respond to some of the submissions that said that there are no problems or that the problems that do occur are basically isolated events and there is no need for any kind of massive governmental involvement, that existing remedies are sufficient.

The other end, the other extreme, would involve or entail a massive governmental intervention that, for short language, I described as creating a new set of nursing homes. It would involve setting standards, having inspectors, probably involve ongoing, per diem funding. Presumably these would be low level or first-stage nursing homes.

Obviously I cannot tell you this morning the direction in which we are going or the recommendations we have adopted, but I think the point that is really relevant for your work this morning is that whatever path I recommend, advocacy is absolutely essential.

If we were to pursue the minimalist path, if I can describe it that way, that would basically mean people should be left to take care of these problems on their own, and many people do not have the human resources, the financial resources, to solve their problems on their own. Many persons with psychiatric histories are effectively placed in pretty awful boardinghomes. They are placed there by hospital discharge planners who have nowhere else to place them. To do nothing, if that was the path we were to recommend, at the very least would mean there is some ethical obligation on the government of Ontario to give these people some assistance so that at least on an individual basis they can try to get out of these places and find somewhere more acceptable or more to their liking to live.

If we take the minimalist path, I think the idea of having supports of various sorts, which includes families for those who have families—but many of the population I am dealing with have no families, and for these people assistance and support is absolutely essential.

If we went the other route, the maximalist path, if I can call it that, and created in effect a new set of nursing homes, I think we would all understand that even a system that involves huge numbers of state inspectors, aside from being very expensive, does not always produce the desired results. I had a large number of people come and talk to me about problems in nursing homes, because they were not aware of the legal distinction between a nursing home and unregulated accommodation, but the basic issue is that a system, such as that of nursing homes, that relies on inspectors cannot have inspectors at all times in all places, and the problem remains, what happens when there is no inspector there?

We had a long discussion about this particular issue in terms of trying to ensure a minimum nutritional standard for the food in the lodging homes in one large city, that there was no way through a system of governmental inspectors that we could be ensured that people's minimum nutritional standards would be met when inspectors are not there. Of course, the idea of having an inspector on site in every rest or retirement home in the province at all times is economically a non-starter and it is not desirable anyway.

I think the central point in terms of the work I have been doing is that a system of advocacy is absolutely essential, regardless of how we choose to respond to these kinds of social problems. I am defining, then, advocacy as a necessary condition. It is not necessarily a sufficient condition, but it is a necessary condition for whatever else we are going to try and do, assuming we want to do something.

I would like to take a couple of minutes to put this discussion of advocacy within a broader historical context. In real life, when I am not being a commissioner, I am a professor at the University of Toronto. I talk to my students about evolutions in the welfare state. I am certainly not going to put you to sleep, like I put my students to sleep, with a two-hour lecture, but I will give you a five-minute overview of how I see the historical development of the welfare state.

I see that there have been three phases to the post-war welfare state. The first one, beginning in 1945, began with the work of Beveridge in Britain and the Marsh report in Canada, and this was the building, the initial creation of the welfare state. It led to all the major social programs that emerged in the post-war period: family allowance, old age security, UI, hospitalization. This phase reached its culmination in the 1960s with the Canada pension plan, Canada assistance plan and medicare. The premise that underlay this first stage I think was that massive and direct governmental intervention was both necessary and appropriate to ensure that people's needs were met, and that no other approach would work.

Beginning in the mid-1970s, when we had the first traces that there was a fiscal crisis and that maybe an overly simple embrace of Keynes was not the answer, we began to cut back, and we are probably—well, not we are probably; we are definitely still in this second phase, where the goal is simply to cut spending. At first we kept many of the forms of the welfare state and we simply starved the programs by not funding them adequately. More recently, of course, we are making major structural changes in some of the programs themselves. But I think the important point in terms of this second phase of the welfare state is that we cared less about the consequences of our action and we cared more about the cost savings that were essential.

The best example of this, and one I am sure you have had presented to you over and over again, was the shutting down of the large psychiatric hospitals. Instead of ensuring that people would be able to cope when they went out into the community, all we cared about was shutting down the hospitals. Initially it was simply to save money. Later we had these clinical rationalizations that had to do with normalization and theories of this sort. But at no time did we ever

put in the time, the money and the resources to ensure that people would be able to cope.

The result is that we turned people out of the psychiatric hospitals; we gave them inadequate family benefits, a Gains-D cheque, a firm handshake and wished them luck. The result was the kind of problems I have had to deal with for the last 14 months. The result, if I can be Toronto-centred, was the squalid housing in Parkdale. I have discovered that there is comparable squalid housing in the catchment areas of many of the other psychiatric hospitals around the province as well.

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These are not discrete historical events. They overlap. But the third stage of the welfare state—I describe it as a welfare society rather than a welfare state—really began, I suppose, with the O'Sullivan report. The Social Assistance Review Committee report called *Transitions* fed into this. The work of the Graham committee with community mental health was in this line and my report will follow in this broad tradition as well. This basically builds on the weaknesses of both the first two models. It accepts that today in 1992 we can no longer afford the new, big, welfare measures programs such as we were able to introduce after the war. Maybe those programs did not deliver all that we hoped for. Maybe our expectations of them were unrealistic. That is my personal view. In any case, the free trade agreement probably would not allow us to develop new major welfare state measures if we wanted to, but I think the bottom line is that we do not have the money or we are not prepared to devote the tax dollars to developing those programs.

I think it also builds on an understanding that this second phase of the welfare state, what we could call the abandonment model, does not work either and that the idea of simply putting people out on the street and wishing them luck is not a humane or compassionate response for a relatively affluent society.

What this third phase tries to do is take the second phase and make it work. It can also be called an "empowerment" model. I know that is a word that is very much in vogue. I saw in the weekend paper that empowerment is the re-election theme of the Major government in Britain, so it is all over the board here. But I think the idea of it is to try to give people the resources and the capacity so that they can function within the economic market, not to abandon people but to give them the resources. These resources include financial resources, but it is more than financial resources. It also includes human resources and human supports and assistance, so that people can function in this market economy in which we live.

The assumption of course is that with support, with assistance, far more people are capable of functioning and coping on their own than we traditionally thought was the case, but it also recognizes that people do need these supports. To repeat myself, the two key supports are money, which is why the reform of social assistance is so important, but the second thing that is really essential is that people must have human supports. Giving people money alone is not the answer. People must have assistance and support to exercise choices, because that is really what we

are talking about. We are talking about enabling people to make choices about how they want to live their lives, where they want to live, with whom they want to live.

Purely in value terms, I suppose, this is more desirable from my viewpoint. People should be encouraged and assisted and supported to make choices about how they want to live their lives. This is far better than having the hospital discharge planners do it alone without the people's involvement. Indeed, in many areas it is better than having inspectors from the nursing homes branch or something of that sort come in and decide what people's needs are or should be.

To the extent you can accept this as a broad, sweeping overview of 45 years of the welfare state in Canada, there is a certain historical inevitability to the development of a system of advocacy, to give people supports. The alternative, to repeat myself, is to go back to the shutting down of the psychiatric hospitals and just leaving people to cope. We have the counterpart of this shutting down of the psychiatric hospitals in many of the unregulated accommodation settings I have seen. The quality of life experienced by the people is not radically different from—well, it is the same people, so obviously the quality of life would not be different.

I am aware of the time here. I would like to make a couple of very specific suggestions and then perhaps respond to some questions rather than pretend I am a professor and talk until one minute before the bell rings and everybody gets up and walks out.

I have really just two very specific suggestions. The general comment is that I do see a system of advocacy—to repeat the obvious—as absolutely essential. I think Bill 74 is a very important bill and I do not think we can delay it. I do not think we can wait. I think it is important that it be introduced now. Much of the content of my report and much of the content of a whole variety of other initiatives that are taking place depend crucially on a system of advocacy being in place.

There are two specific suggestions I would like to make. One is that I would like to recommend that the implementation of the other two bills, Bill 108 and Bill 109, be delayed. In doing this I align myself with many community groups. I was quite concerned when I read one of the documents that said the Ministry of Community and Social Services and the Ministry of Health have an estimated 25,000 to 30,000 people for whom guardianship is going to be necessary the day these bills come into place. I do not know whether these are official ministry figures. They were given to me on a secondary basis, but if they are correct I think it is immediately self-evident that if the bills are all enacted at the same time and we suddenly have 25,000 to 30,000 people for whom guardianships are necessary, the whole advocacy initiative will become the handmaiden of Bills 108 and 109. I think it is really essential that the Advocacy Act be given a chance to get up and running before the other bills kick in.

The other issue in the context of this is that to my mind advocacy and guardianship are substitutes; they are not complements. It may be that if the advocacy initiative gets going, a lot, or some—we do not know how many—undefined share of that 25,000 to 30,000 people will not

need guardianships; advocacy will be a far more effective and a far more empowering substitute.

The other specific comment is really to commend the provisions in the bill to contract with community groups to deliver some of the advocacy services. I think this is a really cost-effective and desirable way to go. It is also crucial in this context that there be a separation of service provision from advocacy. One cannot do both at the same time.

I am not really in a position to discuss the line-by-line details of the three bills, because I have not really focused on those in the context of my work. But in the time that remains I would be glad to answer any questions or respond to any comments.

**Mrs Sullivan:** I wish we had more time here. With Mr Lightman's report coming out and his indication that advocacy is key to his report, I think a number of questions arise. I kind of want to give a hint of where I see some of the questions. One is that we have no indication of how your report will integrate with the long-term care plans of the government. I do not know if you want to speak to that now or latterly, but clearly that is a matter of some importance in these issues.

Mr Chair, since this is the last intervenor before the lunch hour, could we take a couple of extra minutes with Mr Lightman? Would the committee give us that permission?

**The Chair:** Do we have unanimous consent? We do.

**Dr Lightman:** I would rather not discuss in detail how the report fits in with the long-term care initiative except to indicate that it is an issue we discuss in some detail. We do discuss our recommendations specifically within the context of long-term care, but I hope you understand that I cannot give you the details this morning. That pre-empts the report.

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**Mrs Sullivan:** I am disappointed in that, because as we are looking at these bills they will have a substantial effect on the implementation of long-term care. Your comments as an intervenor before this committee would be useful.

You have spoken about people you have dealt with who are vulnerable, whether they are psychiatric patients, developmentally disabled or frail elderly who live in retirement homes, rest homes and boardinghouses. You have indicated that you feel those people need either money or assistance to make choices and that you see assistance being available largely through advocacy. We have a bill, however, that makes no definition and does not provide any outline of what an advocate does. Do you think that is adequate?

**Dr Lightman:** First, I would like to correct that I was not saying this assistance would be provided largely through advocacy. In many cases where there is a family or other private arrangements, I do not think the advocacy would be much of an issue. I am saying that advocacy is essential particularly for those people who have no other mechanisms at their disposal.

I think it is quite appropriate that the Advocacy Commission define its own ground rules about what advocacy

means. I have had a chance to look at the three bills only in a very cursory way, but it seems to me that there are reasonable safeguards within the bills in terms of setting boundaries. It is hard for me to imagine a situation where advocates are going to be wandering off, in a sense, looking for trouble. If there is, for example, an arrangement where a family and the individual member of the family are both quite happy with an arrangement, it is hard for me to understand why an advocate would want to go and intervene when there are so many other unmet needs. The advocates will have to define priorities and I assume they would define their priorities in those areas where they see the greatest need, and where the greatest needs are brought to their attention.

**Mrs Sullivan:** I have real concern in that you have come before us as an expert. You have indicated that you are not particularly familiar with the intricacies of the bills. We are very concerned when you suggest there is adequate protection in Bill 74 in relationship to the activities of advocates. We are very concerned indeed that there is no accountability included in the bills for the work of advocates. There is no definition of the work of advocates and the advocates have been given unprecedented powers of entry to do what you have just indicated you did not think they would do: to look for trouble. We all concur that an appropriate role for an advocate is to look for trouble, but in what circumstances, where, how, according to what public standard should the advocate indeed be looking for trouble to protect the vulnerable person?

You have also indicated to us, using your words, to move—I am sorry, I am all over the place, but I just think this is a problematical presentation. You have suggested that massive governmental intervention through first-stage nursing homes, if you see that as a program, would require an inspector in every rest or retirement home.

**Dr Lightman:** No, I said only carried to the extreme. I was not saying that.

**Mrs Sullivan:** Well, carried to the extreme. Have you heard some of the testimony before the committee that would indicate that with these bills in place, there would have to be round-the-clock advocates in every single hospital, nursing home or care facility in the province?

**Dr Lightman:** Clearly that is not going to happen, particularly if the advocacy bill goes forward first. If there are going to be 150 of these advocates—and I gather that is the figure, by definition, by arithmetic—it is not possible that there will be one in every institution.

**Mrs Sullivan:** Then the legislation will fail.

**Dr Lightman:** No.

**Mrs Sullivan:** You cannot do the Consent to Treatment Act with 150 advocates.

**Dr Lightman:** I am not here to talk about the Consent to Treatment Act because I indicated at the outset that I think—

**Mrs Sullivan:** You cannot do the others.

**Dr Lightman:** I do not see how the legislation will fail. I do not see how the Advocacy Act will fail in the absence of an advocate in every institution. The essence of

it is that to a large extent I would assume the advocacy would respond to inquiries. With 150 people trying to deal with some 60,000 to 70,000 people in extended care beds, plus an undefined number in the accommodation I am dealing with, plus, plus, plus, it is hard for me to understand, just logically and intuitively, why they would go looking for trouble, to use that phrase. It just does not make sense to me.

**Mrs Sullivan:** Your understanding of the Consent to Treatment Act is clearly different than ours. Every health practitioner is required to do a capacity assessment in order to obtain consent to treatment. Subsequent to finding a person incapable of consent to treatment, Bill 109 requires that an advocate be brought in to provide rights advocacy, statutory rights advice, to that person. In order for treatment to proceed, the rights advice has to be given quickly, and every single health practitioner, group or agency that has been before the committee has indicated that the advocate would have to be on site.

I will tell you that if you look at all the institutions all the time, when Mrs Ziemba speaks about 150 advocates in the province, she is dreaming in technicolor. Frankly the larger problems you are talking about will simply not be handled no matter which bill comes in first.

**Dr Lightman:** I substantially agree with what you are saying, which is why I am recommending that Bill 108 and Bill 109 be delayed in their implementation. If they do all go forward at the same time, the advocates will go crazy trying to deal with all the applications for guardianship. That is why I think the implementation of the bills should be delayed.

**Mrs Sullivan:** We will look forward to your report. We have a lot of other questions to put to you not only about this legislation but about your report as well.

**Dr Lightman:** I look forward to it.

**Mrs Sullivan:** I feel badly that we cannot do it at this time, that we do not have the report for your appearance in front of us. I feel there are a lot of unexplored questions that are a matter of very real public importance.

**Dr Lightman:** I look forward to the opportunity to discuss it with you later.

**Mr Sterling:** I am very intrigued by your presentation in some regards and somewhat concerned with regard to some of the directions that you anticipate and recommend we go in Ontario in the future.

First of all, I agree about the deinstitutionalization of some of our residential psychiatric institutions. I think it has been extremely mean to the residents. I think in a lot of cases the homes you have been dealing with have not been producing an equal level of happiness for those people. It has been much less than they were receiving in the institutions. These people have not even been given the choice of returning to those institutions if they so choose, which I find weird in terms of political reasoning. I think what has been tried over the past 10 years has been for all of us to be politically correct and to deinstitutionalize people regardless of tracing these people as to whether they are happy.

I agree with you very much in terms of your assessment of that, but one of the hard facts we have to deal with

is that the resources are limited. My concern is the efficiency of the system so we are able to provide to those who are vulnerable in our society the most bang for their bucks. My concern about bringing in another level of "social worker" who perhaps is not providing a hard service—shelter, food, clothing, whatever—is that you are going to take away from those hard services that we can provide. Whatever you come up with, are you going to deal with the efficiency argument?

**Dr Lightman:** Yes, I am, and I could make a couple of comments about it. It seems to me that the cheap option, the least costly option, which is to do nothing, is what led to the problem with the shutting down of the psychiatric hospitals. From my viewpoint, in terms of my own value system, the question of not spending money is not on the table. The question is, precisely in the terms you said, how do we spend it so as to get the best bang for the dollar? How do we get the most cost-efficient use of the dollars we spend?

It is my sense that a system that enables people to make their own decisions, which is what advocacy is intended to do, is going to be much more efficient than any other alternative I have considered. A system of advocates that helps people to make their own decisions around food and clothing and the other examples you gave is going to be much less costly to the provincial treasury than having another layer of social workers go out and actually give them the food or give them the housing. The social work model is a very inefficient one. I see this as an alternative because one advocate can help a lot more people to arrange for their food, if we want to use that example, than if he or she were directly providing the food. The direct provision is very inefficient. The way I see this, one advocate can deal with a wide array of clients or residents or individuals and can do so in a lot more efficient way than any other system of provision.

1230

**Mr Sterling:** Can I go on with another part of your presentation I am a little concerned about? I think it was touched on when you were talking with Mrs Sullivan about the number of advocates and the number of clients and that kind of thing.

This committee has talked about levels of advocacy over the past public hearings that have gone on for four or five weeks. There has been a different perception, in my view, on the part of people who have come in front of the committee as to what these advocates are going to be able to do. The people who in general have been supportive of advocates view them, I believe, as friends of the vulnerable person. In other words, they are going to be there for these people who in a lot of cases have nobody else to rely on.

I call my previous example the first level of advocacy, something that I think an adult protection worker may be providing in a lot of our communities in Ontario. I believe there are 175 of those in this province. The second level of advocacy deals with the more difficult issues a vulnerable person might face. The trigger mechanism, if there are only 150 or even twice that number in Ontario, has to be

something that is much more formal. In other words, under this system or under this bill I do not view an advocate as being able to go into rest homes on a continual basis. I do not believe he or she would ever arrive at a rest home unless called by someone. Are you viewing this advocacy system as advocacy at that second level?

**Dr Lightman:** To be quite honest, I have not thought it through. I had not thought of it previously in terms of those two levels. I just make the general comment that the Advocacy Commission will have to decide its priorities because the need, the demand, will be so much greater than the supply is ever going to be that they will have to define priorities. We hope the priorities will not simply respond to squeaky wheels. That is the wrong way to allocate resources. I would assume that one of the first tasks before the Advocacy Commission will be to define a set of priorities and decide whether level one or level two would be the most appropriate or the most essential.

If I can make a personal comment, I teach in the school of social work at the University of Toronto and am very aware of the difficulties or dangers that are inherent in creating a person called a social worker. Call them God, make them omnipotent and they will go out and solve everybody's problems, and in all too many cases they wind up doing nothing. I have not had any formal conversations on this topic, but informally I have some former students who have been involved in parts of the legislative drafting and they are very aware that they do not want to create simply another system of social workers here. That is not the intent, but of course you cannot guarantee the outcome.

**Mr Sterling:** In your example that you raised about a person in one of these homes who wanted to get out of the home or wanted to seek alternative accommodation, I cannot see, number one, how that person is going to know there is an advocate around and, number two, whether an advocate is going to have time to be concerned about the accommodation of this individual. You are quite aware of what the adult protection service worker does. Would you not argue for an expansion of their role or a doubling or tripling of their numbers rather than setting up another bureaucracy like the Advocacy Commission?

**Dr Lightman:** The APSWs deal only with persons with developmental disabilities and their clients.

**Mr Sterling:** Expand their role. According to their testimony in front of this committee, they spend about 40% of their time on advocacy issues for their clients. Would it not be more fruitful, in terms of the protection of the people whom you talking about who are—

**Dr Lightman:** Some of whom are, yes.

**Mr Sterling:** Yes. A lot of them are from that area. Would it not be more fruitful for the government to expand their role?

**Dr Lightman:** I do not know enough about the details of how the APSW scheme works to comment on that.

**Mr J. Wilson:** Thank you, Dr Lightman. I know you are well-intentioned to come before this committee and promote the principle of advocacy, but in doing so and not

having studied the bills, it is as if you come and support the government's position.

We are not dealing here with the principle of advocacy, because we are long past that in this province. We have agreement among the parties that the principle is important, but we are dealing with the provisions and the content of specific legislation. Every time we take a run at the content of that specific legislation, we as politicians face the prospect that some group will misinterpret it that we are not in favour of advocacy. Mr Sterling and Mr Jackson have been champions of this for years in terms of talking about the institutionalization and the need for follow-up and all kinds of things dealing with advocacy.

Having said that, I am very interested. I am sorry I missed your course in the evolution of the welfare state when I was at the U of T. I am sorry I missed it because I do not think I agree with you.

**Dr Lightman:** You could attend the course; no problem.

**Mr J. Wilson:** Thanks. You are objective, anyway.

It seems to me that what we do not talk about in this stage of the welfare state—we have never talked about it in the 18 months I have been in Parliament. My party has talked about it, but we never talk about the opportunity that government should be creating out there for people. The greatest dignity I believe you can give a human being in a free market is the opportunity for employment. All we ever talk about is, how can the state intervene in people's lives or how can the state set up another layer of bureaucracy or program to so-called help these people out? In the process, you know very well as an economist that resources are limited. This legislation proposes to spend anywhere from \$46 million just for the public guardian and trustee's office—that is from the horse's mouth—and there are the untold millions it will put on the current health care system.

Where I agree with some of my colleagues is that I do not see how setting up another layer of advocacy services is all that helpful. Should we not be saying to the government, "Look, you should get taxes in line; the province works best when there is opportunity for employment"?

On that, I am interested in reading your report. I just wonder if you can tell us today, to what extent does the high level of unemployment play in terms of people being ghettoized in these unregulated settings, or to what extent does the lack of community resources out there now play? Are we really helping them by providing them with an advocate who may say, "By the way, you need new housing. You need a job. You are capable of working"? But that is fine; you have added another layer of voices called advocates. But there are not the jobs; there is not the housing; there are not the community resources. So I would ask for your comments on that.

**Dr Lightman:** Clearly the availability of jobs and the availability of meaningful employment opportunities would go a long way towards solving the problems, if we can call them that, of a vast array of people. But if I had issued a report that simply said, "You have to go out and create jobs," the report would have been consigned to the

archives very quickly. At the same time as one should be attempting to create jobs, one also has to deal with the present situation: that the economy is in very bad shape and that the most marginal members of the workforce are the last to be hired, the first to be discharged. When we now have unemployment levels that are hitting well into the middle class, it is perhaps naïve in the short term to talk about massive job opportunities or job creation opportunities.

1240

**Mr J. Wilson:** I do not think it is naïve at all. The spiral we are on now is clearly not the way to go.

**Dr Lightman:** I could not agree more. I completely agree.

**Mr J. Wilson:** In your commission, I assume, your report is going to identify probably a lot of what we already know from the horror stories we have heard. I gather the purpose of your commission is to bring forward to politicians and the public the real needs that are out there, but I just disagree with you in terms of adding another layer of advocates to address those needs.

**Dr Lightman:** I would view the advocates not as being job counsellors because they are not intended to provide direct service.

**Mr J. Wilson:** Jobs are just one example of the need out there.

**Dr Lightman:** Okay, but it is a very important one. An advocate should be in a position to assist any person living in a boardinghome or anywhere else, who has any thoughts about wanting to work, in heading towards training or whatever else. I am not naïve about the prospects of training or the outcomes of training or employment, job creation. The economic forecast for this country for the next few years is not terribly optimistic. I certainly endorse everything that the provincial and the federal governments can do to expand the economy. I am in favour of stimulating the economy, and I do not believe the economic policies that have been followed for the last decade have been in any way constructive or productive for anybody except a very small number within the population.

But I have to, in a sense, take as given, at least in the short term, that the unemployment situation is going to be bad, is going to remain bad. What an advocate can do is assist anyone who wants to make whatever efforts they can. They can direct them into the appropriate avenues. They can be an information provider. That is an extremely important function.

**Mr J. Wilson:** I will tell you that is what our office is to do, as MPPs, every day.

**Dr Lightman:** Sure.

**Mr J. Wilson:** You go to direct someone, and there is nothing there to direct them to.

**Dr Lightman:** I quite understand that.

**Mrs Sullivan:** How do you see the difference, then, between an advocate and a social worker?

**Dr Lightman:** I am reluctant to answer that because I will get in trouble with my department. I think too often in practice—not necessarily in theory, but in practice—social

workers fall into the trap of making decisions on behalf of their clients. We have to spend a lot of time in our educational process persuading social workers that even though they are better educated in many cases than their clients and in many cases maybe they do know the answer, you cannot simply go in and say, "Well, this is how you're going to run your life, and this is what you're going to do." It is a trap that many social workers fall into, and I think one of the important functions of an advocate, however it is defined—I think it is inherent in the definition of "advocacy"—is that they will not go in and tell people how to run their lives, that they will not make decisions on behalf of people, but rather they will assist people to make their own decisions whenever and to the maximum extent possible.

**Mrs Sullivan:** We might be more confident if there were any definitions of "advocacy" in the bill.

**Dr Lightman:** Yes, I understand your point.

**Ms Carter:** Dr Lightman, you have reminded us of the original reasons for the Advocacy Act, the impetus behind it, and you have reminded us of the people who have no family or friends. We have constantly been told that this is going to interfere with family, interfere with people, care givers and so on, who are trying to help somebody. But of course the point is that not everybody has that. Could you give us some examples of the kind of problems you have uncovered in your research, in your experience, where an advocate is needed?

**Dr Lightman:** Probably an advocate is needed in every problem I have had drawn to my attention. Let's go back to this example of substandard quality of food. There is a requirement, as a condition of getting general welfare assistance funding for hostels in this community, that a minimum nutritional standard be met. I was told—not I; the community was studying this. Their own report they had commissioned showed that when inspectors were present, the food met the minimum nutritional standards. When inspectors were not present, the food did not meet the minimum nutritional standards. Their own report even had a telephone call from someone who worked in the kitchen of one of these homes who was reporting on this.

If there was an advocate in that context, an advocate would be able to direct the residents to some appropriate avenue or some appropriate outcome to ensure that the food not only met the minimum nutritional standards, but maybe that it also tasted good and that they would have some say in setting menus and deciding what they were going to eat so they would not get the same stuff every day.

There was a particular problem about milk, because the minimum milk standard could be met with powdered skim milk. The report showed that in some cases, even this minimum standard was often being watered down, like, below the level. Many of the residents said they would like to have 2% milk, and at present there is no mechanism through which they can articulate this request. All they can do is talk to the public health nurse or the inspector who comes by and ask him or her to act on their behalf. It is totally disempowering to the residents, because they have

no direct avenue to express their wishes. All they can do is ask the—

**Mrs Sullivan:** What would be the difference between the role of the health official and the advocate?

**Dr Lightman:** The public health official is there to determine whether or not the minimum standard is met, presumably. The advocate would not be there to measure whether or not the minimum standard is met; the advocate would be there to assist the residents to identify an appropriate mechanism through which to redress their concerns.

**Mrs Sullivan:** The advocate would then go to the public health official.

**Ms Carter:** Yes.

**The Chair:** Excuse me, Ms Carter has the floor.

**Dr Lightman:** No, the advocate would not go the public health official. The advocate would direct the residents to go and would assist them to get there, in a sense.

**Ms Carter:** So one person's complaint could lead to something that would solve a problem that was institution-wide, as it were. Do you feel that Bill 74 adequately provides for people to have support to make their own choices, or do you think it could be amended in any way that would strengthen that function?

**Dr Lightman:** No, I think it is a bill that goes in the right direction. I do not have specific recommendations, except for the delay in the implementation in Bill 108 and Bill 109 to give the advocacy bill or the advocacy program a chance to get going.

**Ms Carter:** Another thought that was suggested by what you said just now is that where you have services given for profit and people are tempted to maybe do things in a cheap way rather than in the way that is best for the customers, sometimes we do need legislation and so on to keep the balance between the private enterprise on the one side, which is desirable in itself but which may not always give the best possible results, so the needs of these people are taken care of.

**Dr Lightman:** I do not think non-profit settings are completely devoid of problems. I do not think we can simply say that the non-profit sector is always the good guys and the for-profit sector always the bad guys. It does not break down that way.

**Ms Carter:** But an intervention of this kind could just help to keep the balance.

**Dr Lightman:** Perhaps.

**Mr Wessinger:** I was just interested in your suggestion concerning your problems about—I gather your concern is that you do not want to see advocacy services involved heavily in the other two acts and that is the reason you wish the delay. Is that correct?

**Dr Lightman:** I am not sure I would even necessarily want to take it that far. I think it is to give the advocacy program a chance to get going before it gets swallowed up in these other two. I do not really know whether if I were drafting the bill—which I am not—I would want the advocates involved with those other two bills.

**Mr Wessinger:** That was really my next question. You would not want to express an opinion on whether, for instance in Bill 109, one of the ways of dealing with it might be to reduce the role of the advocates and—

**Dr Lightman:** I am aware that those suggestions have been put forward and that would be another possibility.

**Mr Wessinger:** Would that be acceptable to you?

**Dr Lightman:** Yes, the means is of secondary importance to me.

**The Chair:** Mr Lightman, on behalf of this committee, I would like to thank you for taking the time out this morning and coming and giving us your presentation.

**Dr Lightman:** Thank you for your time.

**The Chair:** One quick announcement: The subcommittee meeting will not be held later this afternoon; it will be held at noon tomorrow. This committee stands adjourned until 2 o'clock this afternoon.

The committee recessed at 1255.

## AFTERNOON SITTING

The committee resumed at 1414.

ISOBEL HILL

**The Chair:** I call this committee back to order. I would like to call forward our next presenter, Isobel Hill.

**Mrs Hill:** Good afternoon.

**The Chair:** Good afternoon. Just a reminder that you will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each caucus. As soon as you are comfortable, please identify yourself for the record and then proceed.

**Mrs Hill:** I am Isobel Hill, the mother of a young fellow who has been diagnosed as schizophrenic, and I am speaking as an advocate of a lot of schizophrenic people. Hopefully, you will be an advocate for me in the right places to get some changes made.

I begin with an introduction to myself so you will understand my concerns, experiences, studies, the authorities I have consulted and then you can judge for yourself the validity of my conclusions.

Four and a half years ago, our son's periodic episodes of violent destructiveness took a turn for the worse when one day he hit out at me and floored my husband. Terrified, we immediately called the police. When two officers arrived and told Brian to talk he floored them both in one second. The officers had to fight for their lives to get him handcuffed. There was no doubt in their minds that Brian was mentally ill and a danger to others. They took him to the York-Finch General Hospital. Here he was sedated with Haldol and kept under observation for three months until there was room for him at the Queen Street Mental Health Centre.

In this way, we escaped all the problems of other parents who experience difficulty in getting their young people committed for help. I sympathize with these other parents' frustrations and hope something can be done to make things easier for them.

At the Queen Street hospital, Brian was assessed as schizophrenic, placed on the second floor for treatment and shortly after was moved to the fifth floor for long-term treatment. In the beginning I visited him almost every day and so had ample opportunity to observe quietly the other patients too, the ones who tried to escape and the ones on the outside phone begging desperately: "Get me out of here. I don't belong here. They're doing awful things to me."

For myself, I had a lot to learn. I admired the work of the staff. They were very cooperative in explaining their procedures and expectations and I cooperated with them fully. In time, I cut my visits to three times a week. I overcame my fear of the other patients when I learned that if they approached me, all I had to do was to be completely honest with them. In this way I became personally interested in the progress of a number of the other patients. But

again I heard the same refrain: "They are doing awful things to me. Pray for me."

On the advice of the staff, I joined the Ontario Friends of Schizophrenics, and June Beeby said we should read all that we can about this condition so that we can speak intelligently to the authorities.

This I have done. I have clipped every scrap of new research published in the papers. I have followed this up by reading books on this research and attending forums at Queen Street, the Ciarke Institute of Psychiatry and other places to listen to the people engaged in this research. I have also discovered references to schizophrenia in some of the most surprising places.

One thing that was recurrent in this was the discovery of damage to the limbic system in the brain of many schizophrenics, but oddly there was no follow-up as to why this damage occurred or how it could be corrected.

Fuller Taylor's work with identical twins who have the same DNA appears to negate the theory of any hereditary factor. Barbara Ann Brennan, who cures schizophrenics, writes that it is the hardest of all diseases to cure because the trauma that causes it occurs during, before or shortly after birth.

Another promising study reported that the blood flow in the brain was unevenly distributed, with some parts receiving inadequate supplies, but again no question of why this should be so or how to get the blood to flow properly again.

1420

While all this visiting and studying was going on, my husband and I kept one day a week for our own benefit, our regular visit to a very gifted chiropractor-naturopath because of a very severe sexual dysfunction. A number of years previously I had joined an excellent sensitivity group to learn more about my feelings. From this, I graduated to a primal therapy group to learn more at a deeper level. One day, mention was made there about a chiropractor-naturopath who could make our primaling, as we called it, deeper and easier.

During my first weekend in a primal therapy group I was surprised to re-experience being stuck in the birth canal. It was terrifying and painful. "I'll surely die if mother won't open up and let me out of this pressure cooker." When I finally did manage to wriggle out between Bill's bony ankles, which I had experienced as my mother's pelvic bones, I realized for the first time in my conscious life that I was me and not part of my mother.

In a few months' time I realized I did not need the primal group, but could get all the help I needed from this wonderful practitioner. But what was he doing to me? Why was I getting these memories? One day I was aware that with his manipulation he was gradually getting blood to flow through different parts of my brain, that it was the opening up of my brain that brought back memories of the traumas that had caused the blockage in the first place. Now this continues to be a terrific learning experience, bringing with it great improvements to my health.

Returning to our son Brian: As I learned more, I started being very concerned about the so-called side-effects of the neuroleptic drugs he was being given. Reading about them in the pharmacopoeia, I realized that these drugs damage every life support system in the body. As I saw these effects one by one occurring in him and in the other patients, I became alarmed. How can these neuroleptic drugs make his brain function better if they are making his body sicker? I stopped cooperating with the hospital and started cooperating with Brian's inner being that had been trying desperately for months to make me understand how he suffered from the effects of those drugs, but I had not caught on to his message. We got his weekend leaves extended a day so we could take him with us to our chiropractor-naturopath. Brian's reaction while in the hospital was, "They do the best they know how," but his reaction to our therapist was, "Boy, he knows a lot."

He has been going with us now slightly over a year and each weekend we notice a subtle change for the better. Now his medication is being gradually reduced. His complexion has improved; he can breathe through his nose again. Some tensions are leaving his face. He sometimes laughs. He is taking longer and longer walks. He is making more decisions on his own, like when and where to get his hair cut, and he is at ease when we take him into a restaurant. That may not sound like much, but if you knew him a little while ago, it is a big change.

Six months after he started going with us he was moved from the hospital to a habitat home and he attends the outpatients program at the Queen Street Mental Health Centre. We are very grateful for all the efforts of the countless number of people who have made these supports available to us and now I would like to return something to help other patients.

There are many causes for the hallucinations and illusions typically lumped together and called schizophrenia. An overstressful life situation may bring about a single psychotic episode, which may not recur. An imbalance in the pancreas causing hypoglycaemia can be a contributing cause. This can be controlled with an appropriate diet and the total avoidance of sugar. Dr Hoffer's group, the Canadian Schizophrenia Foundation, in its research has found that various B complex vitamins can greatly reduce schizophrenic signs and symptoms. Dr Carol North tells how an early trauma caused a problem for her which was cleared away by kidney dialysis. Spiritual healers believe that possession by a discarnate spirit can also cause the hearing of voices and great confusion and that this spirit can be exorcised by a spiritualist.

Yet all these different types of schizophrenia are treated by neuroleptic drugs. Now, some patients and their parents are quite happy and content with the use of the neuroleptic drugs, which reduce the amount of dopamine in the brain. I do not want to say anything that is going to upset any parents and patients who are very satisfied, but for the hard-core schizophrenic person with a damaged brain, something else is needed.

Could it not be possible to set up a ward at the Queen Street Mental Health Centre under the jurisdiction of a chiropractor-naturopath where hands-on treatment could

be given, such as our son accepts gladly and finds so beneficial? The facilities are perfect. It would need the staffing of special persons familiar with the reactions to this type of treatment who would not be upset when a patient, working through the trauma of circumcision, wants to walk around naked with a bandage on his penis and a potty in his hand crying, "I can't wee-wee; it hurts too much," or when a patient curls up in the foetal position and cries with the voice of a newborn infant in the infants' ward of a hospital out of loneliness for her mummy. The gymnasium could be used to work out anger safely. The swimming pool, if warmed a bit, could be used to re-experience the pleasures of the early stages in the womb, where there is lots of room. Appropriate diet, vitamins and herbal remedies could be administered. The stay in the hospital would be only long enough for the patients to learn how to cope with the flow of releasing emotions safely on their own, coming in as outpatients to continue their healing. The end results would be people who are loving and who can work at high-energy jobs, whatever their bent is, instead of being a drain on our society.

My material, which has been kindly duplicated for your benefit by the staff here, contains my original proposal to the Queen Street Mental Health Centre in May 1989. It contains my earlier research and includes a diagram of Wilhelm Reich's concept of the cause of all disease, contrasted with perfect health.

It also contains my statement prepared for a forum at the North York Civic Centre on the proposed amendments to the Mental Health Act in the spring of 1990. This contains a printout of that research on the flow of the blood in the brain, which you can see there, and some sketches from a chiropractic handbook which show how adjustments to the spine benefit every life support system in the body, and you can see with the circulation, even to the circulation into the head.

There is a copy of the brochure of the Ontario College of Naturopathic Medicine to give you a realization of how thoroughly and broadly these practitioners are trained.

There is an excerpt from a book by Dr Deepak Chopra, and if you find it difficult to accept the new ideas presented by me, you are not alone.

There is a picture from Dr Frederick LeBoyer's book, *Birth without Violence*, and I want you to note particularly the terror, the agony and the rage in this baby's face. A baby who comes into the world and screams and cries and kicks like that is called a really healthy baby; that is a real lusty crying. I say that shows a child, a baby, an infant, who has been damaged badly and is furious. With my son's anger and his increasing violence, you put that violence in that baby's being into the body of a 40-year-old man, and that is really something.

You have an article there by Frank Jones on the pain of infant circumcision, and I think there is an article by Sondra Ray, who shows how your own mode of birth affects your life. I do not know if that one got in. And I brought along some books you might be interested in seeing.

Now that I have spread my bread upon the waters, I am ready for your questions.

1430

**The Chair:** Thank you. You have about five minutes each.

**Mrs Sullivan:** Mrs Hill, I was interested in a portion of your testimony that indicated that when you became aware of some of the effects your son expressed to you about the effects of the neuroleptic drugs, to quote you, you "stopped cooperating with the hospital." What did that mean? Did that mean you ceased to give consent for treatment with neuroleptics at the hospital?

**Mrs Hill:** It means I started listening to Brian. I started listening to my son, and in his own convoluted way he was expressing to me the pain he was going through with these drugs, so I arranged to get him to go to a chiropractor-naturopath. That is what I meant.

**Mrs Sullivan:** So in terms of your own relationship with the hospital, there was no effectual change in terms of—

**Mrs Hill:** I have very good relations with the people in the hospital, yes. They are good people. As Brian says, they do the best they can.

**Mrs Sullivan:** Good. The next question then is, when Brian began the naturopathic treatment, that was an adjunct to continuing care at the hospital until he became an outpatient, is that right?

**Mrs Hill:** That is right.

**Mrs Sullivan:** During the period he was receiving that care, was there any necessity for consent to be given for that care from the chiropractor?

**Mrs Hill:** I was told they did not object to chiropractors. They had nothing against chiropractors.

**Mrs Sullivan:** Was the chiropractor obliged to make an assessment of his capacity?

**Mrs Hill:** Pardon me. He is a chiropractor-naturopath. A chiropractor alone is not enough, but a chiropractor-naturopath has extra talents.

**Mrs Sullivan:** I see. Your son is now an outpatient at the Queen Street Mental Health Centre? That continues?

**Mrs Hill:** That is right.

**Mrs Sullivan:** Does he continue both the therapy from the Queen Street Mental Health Centre along with the therapy from the chiropractor-naturopath?

**Mrs Hill:** That is right, and he will have to be under the care of the hospital until he is off the neuroleptic drugs. Of necessity, they have to be reduced very slowly. The doctor there is very conscientious, but the amount of the drug is now reduced by a third and Brian is coping very well.

**Mr J. Wilson:** Thank you, Mrs Hill. It is very interesting reading. What has the response been to your proposal that was put forward to the Queen Street Mental Health Centre? Have you received a response to date?

**Mrs Hill:** The response has been that they cannot do anything like this because they are under the Canadian mental health department and that this is unproven. So I thought, okay, if it is unproven, then we will give you an

example. That is why we went ahead and worked with Brian.

**Mr J. Wilson:** Good for you. Just in reference to the bills that are before this committee, have you had a chance to scan through the Advocacy Act or the Consent to Treatment Act and do you have any comments on those acts?

**Mrs Hill:** I think possibly the thing that bothers me with the Mental Health Act is this business of trying to get the patients under care. My feeling is that those patients do not want that kind of care. If we can do something to change the kind of care they get, they may not be so adamantly against it.

**Mr J. Wilson:** Does your chiropractic-naturopath have any other patients who are schizophrenic?

**Mrs Hill:** I do not know, but I do know there is one guy who comes in there, and whenever he comes in, we all postpone our treatment and let him go in because he is paranoid and he cannot stand any crowds.

**Ms Carter:** I certainly find this an interesting approach, but I am just wondering. You are a member of Friends of Schizophrenics. I am just wondering how your associates in that group react to the kind of approach you are taking and the kind of thing you are doing.

**Mrs Hill:** I am a rebel. I am trying to educate the Friends of Schizophrenics, because I feel I am a real friend. When I go to the meetings, I feel they are playing a psychological game called, "Ain't it awful?" It goes round and round in circles and it ends up, "We can't do anything." It does not get anywhere. So I am trying to educate them, but it is hard work.

**Ms Carter:** You are certainly much more upbeat than some of the parents of schizophrenics we have heard from, and I certainly hope your son will have a full recovery.

**Mrs Hill:** I know he is. I do not have any doubts about it.

**The Chair:** Mrs Hill, on behalf of this committee I would like to thank you for taking the time out this afternoon and coming and giving us your presentation.

**Mrs Hill:** Thank you, and thank the person who did not turn up so I could get here. Thank you very much for your patience.

#### ONTARIO PSYCHIATRIC ASSOCIATION

**The Chair:** I would like to call forward our next presenter, from the Ontario Psychiatric Association. Good afternoon. Just a reminder: You will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Dr Hoffman:** I will limit myself to 15 minutes in my presentation. I am Dr Brian Hoffman. I am a psychiatrist. I am the director of the psychiatric day treatment centre at Mount Sinai Hospital and I am an associate professor of psychiatry at the university, so I teach medical students and residents about psychiatry. I have been in practice for 26 years. I am here on behalf of the Ontario Psychiatric

Association because for the past eight years I have chaired a committee that has been examining all the legislation and proposed legislation that affects the mental health and treatment of citizens in Ontario.

Just to remind you, the psychiatrists in Ontario number about 1,000, close to 1,100. We have all done our medical training and our internship, and they take a minimum of seven years. In addition, we have taken at least another four years learning psychiatry and how to treat those who are mentally ill.

Members of our organization, in particular members of my committee, have met with a large number of other organizations about these laws. We have met with the Ontario Medical Association, the Ontario Hospital Association and the Ontario Friends of Schizophrenics. We have met with the staff of the Ministry of Health, when they have been available, the faculties of medicine, interest groups within the nursing profession and interest groups among the legal profession, some of whom are most senior and from the rank and file of their group.

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I personally have had the pleasure to work with David Weisstub on the commission on competency, and we had many long discussions. Some of us travelled with him, using private money, to Israel to meet with experts from many different countries of the world, people who work in government, law and medicine and are involved in the field of competency, advocacy, legal rights and the protection of rights.

Let me say that there is not one other country or jurisdiction in the world that currently has laws such as the proposed laws that would interfere with treatment as much as these laws, as currently drafted, would. There has usually been consensus that the best protection for the patient is a competent, caring physician. The law and advocacy should step in when things go wrong. If the law gets involved too early, physicians will practise defensively, avoid the seriously ill and do what is legally safe. That is why these other countries have not moved to the same degree, even though they have better laws, in my opinion, on areas of advance directives, living wills and rights protection.

As members of my profession watch the proceedings of this committee we are troubled. We see that there is a relative uniformity of opinion of all of the above organizations we have met with, but despite all the hearings and all the briefs the government has produced no amendments. The government has allowed no extensions of time for further consultations. There has been no allowance for discussions of amendments from those who will be affected by them. It is our perception that we appear to have a government that consults but does not listen.

Finally, we are troubled by rumours that this government does not want or respect the opinion of professionals. It will not consult with them. The professionals were not consulted when this law was drafted. We will not be consulted, apparently, when the amendments are brought down. We have never been shown any amendments.

We are further troubled that this government, I am told—rumours—believes that Bill 74 is the most valuable

of the bills and that it would be acceptable to most professionals even without Bills 109 and 110.

I can tell you that the public is watching. I believe the public wants a government that is passionate but listens to reason. Unfortunately there is a perception and the fear that this government is passionate but that it has a history of passing legislation unchanged even after vociferous and rational arguments for amendment.

I want to cover three areas, and I have put these into the handout I have circulated: some strengths of the bills as we now see them, some weaknesses of the bills and some general recommendations for change.

The strengths are numerous and important. The legislation provides clear laws on advance directives, living wills and the use of powers of attorney and guardianship. We need these. Some of the phrasing is awkward, such as "wishes," but this could be hammered out. The proposed legislation gives a clear definition of who is competent and who has the right to accept or refuse treatment and who does not have the right to accept or refuse treatment. It protects the rights of competent patients. There is a clear hierarchical list of substitute decision-makers, including things that are not currently in our law: common-law spouses and homosexual lovers. It is good that the law outlines the basis of substitute decision-makers' decisions. There is advocacy for those who identify it as abuse. In my opinion, the real value of these three bills lies in Bills 109 and 110. With minor modifications, true progress and value can be found for both medicine and legal rights.

But some of the weaknesses: First, most of the organizations we have consulted find Bill 74 to be totally unworkable. To name a few, these include the Ontario Psychiatric Association, the Ontario Medical Association, the Ontario Friends of Schizophrenics, the Ontario Hospital Association, the Ontario Psychological Association, the faculties of medicine, the Registered Nursing Association of Ontario, the Victorian Order of Nurses of Ontario, the Ontario Nursing Home Association and the Ontario Long Term Residential Care Association. Hear these organizations. There is uniformity of opinion.

Second, the rights of the incompetent patient are not protected. I said the strength is that the rights of the competent patient are protected, but the rights of the incompetent patient are not protected. You give incompetent patients the right to refuse treatment and, through a system of incompetent appeals, resist treatment indefinitely. If you view incompetent patients the same as our children, they deserve timely and effective treatment, and it is the job of society to make sure this treatment is available while respecting their rights.

Third, you are creating an adversarial system within the field of medicine. The law talks of rights, but it does not talk of treatment. Should the laws not direct attention to the rights of the competent patient and the rights and treatment of the incompetent patient? Advocates are given the directive to act on patient instructions. Advocates and lawyers, however, have no written guidelines or ethical standards on when they should not act on an incompetent patient's instructions, a point made by Professor Weisstub in his 500-page report.

Fourth, review boards in psychiatry, as they now stand, and you want to extend this to all of medicine, often take three hours. Last week, one at Mount Sinai Hospital took eight hours. The psychiatrist must attend this. The longest review board I have seen was 10 full days spread over three weeks. Is this what you expect a neurosurgeon or an internist to do when a patient is delirious and refusing to comply with treatment?

Fifth, as written, the powers of the advocate are powerful—too powerful. They are in fact police powers without accountability, training or liability.

Sixth, one reason I am here today rather than merging our stand with the Ontario Medical Association's is that not enough was said that there are two areas in these laws that discriminate against psychiatric patients. Some of the advance directives of psychiatric patients are ignored when the advance directives of no one else could be ignored.

For example, a schizophrenic who is competent, and they usually are on an outpatient basis, may want to write an advance directive that he wants to be admitted to hospital and treated with anti-psychotic medication when he becomes psychotic. He wants to be protected from his own incompetence. According to this legislation, a substitute decision-maker or a guardian could not do this unless he went to court for a court order. In no other group does the law override such an advance directive—with Alzheimer's disease, with mentally retarded, with coma.

A second example is, guardians cannot sign patients into a psychiatric facility on their own belief system as to what is required. You could get them into neurology or you might be able to get them into neurosurgery for a brain operation, but you cannot get the same patient with much of the same pathology into a psychiatric ward where we can provide psychotherapy, group therapy, family therapy and we have a better knowledge of medications that might avoid some of the more intrusive medical treatments.

Even though psychiatrists are doctors and work in a general hospital, the law treats us as jailers working in a prison. More important, such a law ignores the right of incompetent patients to receive the best possible treatment while we are respecting their rights.

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We are not even recommending the use of force. But if any patient is incompetent and has signed an advance directive and the substitute decision-maker wants to sign the person in and the person is willing to stay because that person has that power, then force is not required. If they want to leave, as with the other illnesses and wards I have talked about, the person would be allowed to leave. You could only force them to stay using the Mental Health Act, but to say that a substitute decision-maker would have to take an advance directive to court is discriminatory against psychiatric patients, illnesses and wards.

My seventh point is cost. At a time when this province spends less than \$2 million per year on mental health research, the cost of advocacy is obscene. Schizophrenia does affect 1% of the population at some point in their lives. Severe depression will affect 10% of the population; mania, another 1%. Suicide is the cause of death in 6% of all deaths in Ontario. The morbidity and mortality of these

conditions, which affect the young more than the old, is greater than heart disease, cancer or any other disease, and we spend less than \$2 million a year on research.

The official guardian and the public trustee have both said they would require at least \$25 million to \$30 million to set up an advocacy program for the advocates. This does not take into account the indirect costs of review boards, lawyers' fees, longer lengths of stay and beds tied up, nor does it include patients not admitted at all.

Other problems that could be mentioned—and I will, but I will not describe it in detail with this current legislation: Children will be able to refuse treatment. You have heard the OMA describe that.

Second, the requirement that all risks be outlined is impractical. I cannot do that for an aspirin tablet. Rather, it should be similar to the common-law standard that currently exists in court of common or material risk, plus an obligation to answer the patient's specific questions.

Third, the requirement that emergency treatment can only be provided if there is danger within 12 hours is arbitrary and unrealistic, unworkable. If you have a heart attack, your chance of dying within 12 hours is 12%. The law says a doctor can only intervene if it is likely that will be serious bodily etc harm. Is 12% likely? "Likely," as we use it in law, means more likely than not. You have to hit 51%. If you start using words like "likely" or "probable," you will limit the doctor's ability to help people who need to be helped, including the most obvious one, heart attacks.

Solutions:

1. Look at your priorities. Look at what is lacking. Give some deep thought to the real movement you can make forward in the areas of advance directives, living wills, substitute decision-makers and guidelines for decision-makers. In other words, give a priority to Bills 109 and 110.

2. State in the preamble of these laws that the purpose is to protect the rights of the competent patient and the rights and treatment of the incompetent patient. It is not in the preamble, and if it is not there, advocates will come in and act like lawyers. In psychiatry, for too long we have had advocates come in and think they are trying to get someone out of jail, and it is not jail; it is a hospital. The patients must continue to work with the doctor if they hope to get out of hospital, and the adversarial system is detrimental.

The most vulnerable patients in our society must have their legal rights protected, including the right to effective and timely treatment, which is a right in our society that is given to every other member. You cannot, by your laws, prohibit incompetent patients from receiving treatment when in fact they are refusing on the basis of their illness.

3. Give the legislation writers time to write the revisions that will give the impression that you have listened. Bring back your amendments for further open discussion. You can still meet your deadlines.

4. Provide active advocacy where there is evidence that a patient is or may be abused; for example, on patient complaint or the complaint of any other person.

5. You can cut down the cost of advocacy by allowing paper notification and pinning up of a phone number. If you bring in advocacy when there is no proof of abuse, if

you label every vulnerable adult as abused, you are making a mistake. There is a difference between being a vulnerable adult and being abused and you should wait till there is a complaint before you bring in the very costly system that interferes with treatment.

6. Cut down the adversarial system by instructing hospitals to provide internal advocates that are accountable to the community board.

7. Do not discriminate against psychiatric patients. Their advance directives must be respected the same as other advance directives. Their guardians must have the same powers of admission and treatment order as if their relatives were physically ill. Thank you very much.

**Mrs Sullivan:** Dr Hoffman, this has been a very interesting and useful presentation. To your list of those who have requested that the bills be withdrawn, amendments prepared and this legislation treated as a draft legislation and a new consultation period to follow, we can also add the College of Physicians and Surgeons of Ontario and the College of Nurses of Ontario and many other organizations who have been before us, including Kerry's Place, which deals with autistic people and was here with us this morning.

I am not going to take time to ask you questions, but I am going to ask the parliamentary assistants or their representatives who are here, once again, if the government will now agree to treat these bills as draft bills, to come back with redrafted bills which include amendments, provide time for analysis and review and public hearings before proceeding to clause-by-clause.

Second, I would also like a confirmation of the government's intention, which everyone knows has been rumour for some time, to proceed with Bill 74 rather than with the package of Bills 108, 109, 74 and 110. That is certainly the talk that is out on the street. We would like to have confirmation of the answers to both of those questions.

**Mr Winninger:** I do not think our position has changed, just speaking from the point of view of the Attorney General. We indicated earlier in these proceedings that we were anxious to hear all the presentations, all the deputations before we tabled any possible amendments for review. That position certainly remains intact.

Second, in terms of timing of enactment of these bills, it is my understanding that these three bills will continue to proceed as a package. I would indicate for the record that we have heard from many other presenters that after 10 years of talking and discussing this legislation it is high time the legislation was enacted without any further undue delay. I do not have my list of presenters with me, but one notable one that comes to mind was Carla McKague, a well-respected lawyer with the Advocacy Resource Centre for the Handicapped, who indicated that there had been enough discussion and the time was to act. Speaking from my vantage point, that would be the intention.

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**Mrs Sullivan:** The parliamentary assistant has not indicated if there will be time for consultation and analysis before proceeding to clause-by-clause. Perhaps the parliamen-

tary assistant to the Minister of Citizenship can respond to that question.

**Mr Malkowski:** We have heard from the people presenting here sharing their various opinions. We were here to listen to that first before talking about possible amendments which then could be reviewed at that time. Over the years we have heard many people presenting and there have been many different groups. During previous governments they have also supported the principle of advocacy and we have heard from people that it is now time to start implementing some of what we have heard, through an advocacy system.

**Mrs Sullivan:** On a point of order, Mr Chairman: I want to make it very clear that the consultative document that is specifically referred to in the statements made by the parliamentary assistants was the result of commissions. Since those commissions came forward—I include the Fram commission and the Sean O'Sullivan report—and one document which was issued as a consultative document in the summer of 1990 by the previous government, there has not been consultation. It is unfair, and indeed false, to indicate that there has been consultation on this package of legislation. It is absolutely impossible to believe that the government considers this package of legislation acceptable when every single health care professional, through the organizations in the province, have come forward and asked for the legislation to be withdrawn. It is absolutely unacceptable. That would not have happened had that consultation occurred and that should be very much on the table.

**The Chair:** I might respond that the parliamentary assistants have said that this committee process is the consultation process for this legislation.

**Mrs Sullivan:** Well, it is not enough and it is very clear that it is not enough.

**Mr Sterling:** We are very much concerned about proper consultation. Proper pacing of the legislation, I think, is the way I would rather put it in terms of a bill or a number of bills which could have, I think, a tremendously significant detrimental effect if not drafted properly with a view to how they are going to be implemented. I think they could be disastrous for health care professions—not the professions, but the treatment of the patients.

As I go through these hearings, and we are getting down to the final strokes of these hearings, I am becoming more and more concerned with the general layout of Bills 108 and 109. On Bill 74, I agree with your remarks totally that it is obscene to spend \$30 million on advocates to run around this province and advise people of their rights when we are spending less than \$2 million on mental health research. I agree 100% with you on that. I would rather give the \$30 million to mental health research and forget about the advocates altogether.

Notwithstanding that, on Bills 108 and 109 my support for this legislation came out of the advance directive part. I think it is extremely helpful for the individual, the family and the health care profession to know what the patient wanted done to him or her when he or she was competent. As we go through these and hear from people who represent the

various groups—schizophrenic patients, Alzheimer's patients and people who are just old and have other mental dementia—is it possible for us to draft a consent bill which properly gives these people the question of consent. Is it possible or are we trying to do something that is impossible? Should we perhaps just forget about it and rely on the common law? You would have quite an experience with a number of these groups we are trying to cover in legislation. Would we be better off just going back to the common law, dealing with the advance directives and forgetting about the rest?

**Dr Hoffman:** Yes, if we split off. I was not quite clear whether you wanted me to address advance directives, where there is a real need for legislation, or competency and consent. When the Ministry of Health pulled together a committee to brainstorm issues of consent, there were about 30 lawyers there. I must admit Carla McKague was not there. I think in fact the most senior and respected lawyers in the province were, but Carla was not. There were perhaps three physicians there. It was a meeting chaired by the director of legal services at the Ministry of Health. The lawyers really thought this was a common law issue—competency and consent—that the protections were there, that a physician was bound by law to provide certain things. If he did not, then the patient or his representative had recourse to the hospital, the college or civil court. That is the route that group of senior lawyers really came to. They thought it was a mistake to bring this into legislation.

From my point of view, the legislation is probably somewhat more inflexible than common law. I think common law could grow with the situation, as it has over 30 or 40 years. There may be increased demands. Maybe 10 years from now such information should all be in written form or on computer diskette. I think the courts and the professional colleges will modify common law over time. Personally, I prefer to see that in terms of allowing changes in the future of upgraded standards that you and I could not envision currently.

**Mr Winninger:** Thank you, Dr Hoffman. I would like to clarify a couple of matters with you that I find somewhat confusing.

First of all, you would agree with me that under the common law if someone declines treatment, a guardianship order would have to be taken out to impose treatment on that individual. We are proposing under Bills 108 and 109 what seems to have some appeal to you, a system where there can be guardianship orders made and under section 19 of Bill 109 an individual can actually be admitted to a psychiatric facility and deemed to consent to admission once the guardianship order has been made—

**Dr Hoffman:** No, it is not true. There is another section that says if it is to a psychiatric facility, that can only be brought about through an order of the court.

**Mr Winninger:** Right.

**Dr Hoffman:** So there is a specific exclusion to psychiatric ward.

**Mr Winninger:** Subsection 19(2) says, "If the person is 16 years of age or more and objects to being admitted to

a hospital or psychiatric facility, only a guardian of the person appointed under the Substitute Decisions Act, 1992, has authority...to consent to his or her admission."

**Dr Hoffman:** And that admission must be specifically labelled in the court order that gave him guardianship.

**Mr Winninger:** Right, but that is an advance over the situation now that we heard Ontario Friends of Schizophrenics complain about where there is a revolving door of admission, treatment, release and then non-compliance with treatment.

**Dr Hoffman:** Sure, it is an advance from a situation that is currently unworkable, so I am in favour of it. But why you would discriminate against psychiatric patients and make it unlikely that even a guardian would be able to penetrate the legal system is beyond me.

**Mr Winninger:** Okay. Would you agree with me, Dr Hoffman—I know you have a great deal of background and expertise in these matters—that without the Mental Health Act there would not be any ability to admit or treat, simply because there would not be any civil committal, there would not be any substitute decision-making for psychiatric treatment, as there is under section 35 of the Mental Health Act.

**Dr Hoffman:** Unfortunately we do not know what guidelines the court will use. If you refer the admission to the court, then I have no way of knowing what the guidelines will be under which a judge would so permit this admission to a psychiatric facility. I have no guarantee that it would not be as strict or stricter than the Mental Health Act, which is totally against what you are trying to accomplish.

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**Mr Winninger:** Could I have another moment or two, Mr Chair?

**The Chair:** Mr Malkowski would like a quick comment. It is up to you.

**Mr Winninger:** I will finish up quickly and allow Mr Malkowski.

**The Chair:** We only have one minute left. Your choice.

**Mr Winninger:** I will let Mr Malkowski come in.

**Mr Malkowski:** I will defer to Mr Winninger, if you want to wrap up.

**Mr Winninger:** I will complete my line of questioning then. We have heard from victims of psychiatric abuse. We have had people appear before us in these hearings who have been lobotomized. We have had people appear who have had electroconvulsive therapy treatment and suffered very negative side-effects from that. We have also had people appear before us who have been treated more recently with drugs and suffered adverse effects from that.

Surely the kind of framework that is set up under the Mental Health Act, the review board system, is a small price to pay to ensure that the rights of psychiatric patients are protected. I know you said they go on too long. I have done dozens of review boards, representing patients or the official guardian, and even one hour seemed too much for the psychiatrist to stand to ensure that a reasoned decision

was made either confirming or setting aside the psychiatrist's decision.

You talk about the caring, competent physician. Even premising that all physicians are caring and competent, surely there needs to be some protection for mental patients from the kind of abuse we have had witnessed before us.

**Dr Hoffman:** Yes, I agree. I think what you have to decide is, at what point do you bring in an advocate and an adversarial system? It is clear the rights advisers take an adversarial approach. The Manson report, surveying not just hospital staff but community people, repeatedly reported how adversarial this approach is. I think you have to decide whether you are really going to bring it in every time a patient is incompetent, that is, vulnerable, or when there is some evidence, such as a patient complaint, that something is being done. I think it depends on whether you bring it in at every step, which will mean at least nine cases out of 10. The more judgemental it gets, the longer the review board will be. You want psychiatrists to be there, that is fine. Do you really want your neurosurgeon to be there or your neurologist?

**The Chair:** Dr Hoffman, on behalf of the committee, I would like to thank you for taking the time out this afternoon and giving us your presentation.

#### AIDS ACTION NOW

**The Chair:** I would like to call forward our next presenter, AIDS Action Now. Good afternoon. Just a reminder that you will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Mr Cornwall:** My name is Alan Cornwall. I am a lawyer and I am a member of the steering committee of AIDS Action Now.

AIDS Action Now is a Toronto community-based activist organization, the primary mandate of which is to seek broader and more equitable access to high-quality treatment and health care with particular focus on the needs of people with HIV and AIDS. The primary objective of the organization is to expand the range and the quality of treatment and health care available to people living with AIDS and HIV.

Perhaps I could begin by explaining to the committee the importance of treatment and health care services to people with HIV and AIDS and some general points about the nature of HIV and AIDS as they may be relevant to this proposed legislation.

AIDS manifests as a series of different opportunistic infections in individuals with weakened or compromised immune systems. The weakening of the immune system is believed to be caused by a virus known as HIV. Once infection takes place it is believed that the virus can take many years to damage the immune system, and the damage can be slow and progressive. As AIDS and HIV impair the immune system, the health of most individuals with HIV infection and AIDS is affected by various opportunistic

infections which can range in severity from being mild or chronic to being acute and life threatening. The severity and nature of conditions can vary dramatically over the course of a person's illness.

The wide range of opportunistic infections requires an equally wide range of treatment. In order to be effective, treatment must be early, fast and aggressive. As more and more treatments become available for opportunistic infections and diseases associated with AIDS, the quality of life and the life expectancy of people with HIV and AIDS is increasing to a point where HIV and AIDS has come to be seen by many as a chronic manageable condition rather than as inevitably fatal. However, treatment with respect to HIV-related problems is very complex, and decisions with respect to treatment must be well coordinated and planned.

AIDS Action Now believes that empowering people with HIV and AIDS to make their own health care decisions is vital to the quality of their health. In order to participate in one's own health care decisions one must have full and broad access to all relevant treatment and health care related information. This is particularly critical in the context of HIV and AIDS.

Another point to emphasize is that many people with AIDS and HIV rely upon treatments which are experimental or not approved and rely heavily upon non-traditional remedies and therapies and treatments, not just prescription drugs and traditional medicine.

We believe that the principles of informed consent and the right to delegate decision-making powers must be applied in the context of all treatments. We therefore endorse the broad definition of "treatment" contained in Bill 109, An Act respecting Consent to Treatment, and would strongly object to any narrowing or limitation of this definition or any less of a standard of informed consent.

Before I get into a discussion relating to particular recommendations, there are a few additional facts which may be of interest with respect to AIDS and HIV as they relate to the health care system and situations of people with AIDS and HIV, and I will just make these points quickly. HIV and AIDS is a recognized disability under human rights legislation. People with HIV and AIDS are recognized as disabled by human rights legislation. The groups of individuals affected by HIV and AIDS are communities of people who are particularly marginalized and who routinely face discrimination, and the discrimination is rampant and systemic. Gay men and IV drug users, for instance, and increasingly more and more women and people of colour are affected by AIDS and HIV.

Another particular problem is that the quality of treatment and standards of treatment are generally poor and inconsistent throughout the province. There are very few doctors within the province who specialize in HIV- and AIDS-related illness, and those few doctors bear the burden of providing health care services to a very large patient base. People with AIDS and HIV frequently use hospital services as well.

Another point I would like to make before I go on to refer to specific recommendations relates to the role of the family, and this is particularly relevant in the case of HIV and AIDS. Vulnerable persons must rely upon the good

faith of family members or care givers to recognize, ascertain, explain and enforce the rights of vulnerable persons. While in many instances family members and care givers choose to fulfil their role as such in a responsible manner to the benefit of vulnerable persons, many vulnerable persons are not fortunate enough to have such family members or care givers upon whom they can rely for this purpose.

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In particular, with respect to HIV and AIDS, individuals are often rejected or alienated by their family members upon learning of their infection or illness. It is unfortunately the case that for significant numbers of people infected with HIV or afflicted with AIDS their partners, their care givers and their care arrangements and other wishes are not recognized, let alone respected, by their parents or other legal family members. In many situations, family members do not act in good faith, in the best interests of vulnerable persons with HIV or AIDS. This is particularly so with respect to AIDS and HIV because of the nature of the communities affected.

I have distributed along with our brief a copy of a document entitled *Policy Options 1992*, printed by Aids Action Now, which outlines issues of importance to people with AIDS and HIV. I have distributed it for the purpose of highlighting the broad and complex issues facing people with AIDS and HIV which may require advocacy services. These are the types of issues that advocates may be dealing with in the context of vulnerable persons with HIV and AIDS. A copy of that document has been circulated. I will not make reference to any more particular issues.

I would now like to go on to summarize very briefly some of the major recommendations we have made in our brief, and I would urge everyone to read the entire brief because this is summary only. I have skipped over a number of the points, and I am just going to highlight very quickly some of the major points we are making.

First of all, our first recommendation is that the government make the amendments which we have recommended and proceed as quickly as possible to enact these bills, Bills 74, 108, 109 and 110, into law and to proclaim, enforce and implement them as quickly as possible. In this regard, we endorse the submissions made by the Ontario Advocacy Coalition wholeheartedly. It is our first and primary recommendation. We do endorse the legislation and recognize its usefulness and its need at this time.

The remainder of the recommendations which I will make are outlined in the brief and are more specific or detailed in nature. Rather than explaining the detail behind the recommendations, I will try to state them in a general way that focuses on the principle that we are concerned with rather than the particular language of the recommendation, which you can find in the brief we have submitted.

First of all, as I said earlier, we endorse the broad definition of "treatment" as well as the broad requirements contained in subsection 5(2) of Bill 109, An Act respecting Consent to Treatment, the informed consent requirement. We endorse the inclusion of information being provided before informed consent can be seen to be given of all risks regarding all available treatments and all alternative

courses of action. We think it would be unfortunate if that standard were lessened in any way.

We have also, as a separate recommendation, recommended that the consent statute be amended to include as an offence the provision of any health service without consent in accordance with the Consent to Treatment Act, 1992, and we have recommended that that legislation create an offence for the provision of services without consent.

Third, we have looked at the definition of "partner" that is contained in the legislation, and while we are pleased with the fact that gay and lesbian relationships can be recognized for the purposes of this legislation by health practitioners, we would ask that the definition of "partner" be amended to remove the requirement that others recognize relationships in order for them to be validated for substitute decision-making purposes. When I say "validated," I do not mean through the process, I mean recognized generally. The reason for this recommendation is that a large number of people who are affected by HIV and AIDS live in relationships which are not traditional and have not traditionally been recognized. We find that particularly threatening in a society that has not yet dealt with that discrimination and that problem.

The next recommendation relates to the prioritization of substitute decision-making individuals. You will see in our brief that we have made reference to the fact that subsection 16(1), paragraph 4, includes the recognition of the claim of a partner and a spouse. We would recommend that the partner be given priority because of the cohabitation requirement. We believe that in cases where, for instance, there is a spouse who is no longer cohabiting with an individual, if that individual has a partner, the partner should have priority over the spouse in being a decision-maker on behalf of the incapable person.

We have also made a recommendation with respect to recognition of cohabitation, that cohabitation should be a factor which should cause an individual's claim to prevail. When you look at section 16, the various paragraphs following partner and spouse, we believe that other family members should be given priority in the event they are cohabiting with the individual.

We have made a number of recommendations relating to a general concept that we believe, that is, that people who are affected by a particular disease or illness, or in our case HIV or AIDS, should be allowed to participate and should be actively able to participate in all the decisions which affect them. We believe that the advocacy legislation in its draft form does recognize that principle and does a good job of it. However, we have made other recommendations as to the implementation of that accountability and representation to disabled communities. I will not get into any detail on that. You can read our brief on that point, but we do hope to have participation in the Advocacy Commission, advisory committee status, and also in the affairs of any review board. Generally, I believe disabled people should be participating in the affairs of the Consent and Capacity Review Board.

The next important recommendation relates to the importance and paramountcy of the concepts of privacy and confidentiality of information. Generally speaking, we believe that

the privacy and the confidentiality of medical information is more paramount than any other kind of information and causes more of a concern, particularly to people with HIV and AIDS, because of the discrimination, the stigma and the lack of access to services etc, that people with HIV have faced in the past. We believe this legislation should recognize that problem exists. In this regard we have made a number of recommendations.

With respect to subsection 30(4) of the Advocacy Act, there is a permissive right to release information in circumstances where the advocate believes the person could cause harm to another person. I am not paraphrasing the language directly. Our recommendation is that the release of any such information should be restricted to the purpose of stopping such harm, just as the release of any information should only be permitted for a particular purpose, and only for that purpose, without someone's consent. If the purpose of this subsection is to allow advocates to release information to avoid harm resulting to another person, that should be stated in the legislation.

In addition, we have recommended that in no event should a disclosure of information relate to the vulnerable person's medical condition. We do not believe it is necessary that that information be released, and that is particularly relevant in the context of HIV. We cannot contemplate a situation where the fact that a person is infected with HIV or has AIDS needs to be released for this purpose.

1530

We have other recommendations relating to privacy and confidentiality, and I am coming to a close shortly; it is not going to be much longer. All records, files and information in the hands of the Advocacy Commission should be subject to the privacy and confidentiality provisions of the Advocacy Act, not the Freedom of Information and Protection of Privacy Act. We like the protection that is afforded by the draft legislation with respect to records and we do not believe that the Freedom of Information and Protection of Privacy Act is sufficient in this regard. We have made a recommendation to amend the Advocacy Act provisions on this point.

Another recommendation we have made is one which is probably quite obvious, that is, we believe adequate money and resources have to be allocated when this legislation is put into effect, and in particular we will be concerned with the amount of effort and resources that are put into training and certification of advocates. We would ask for at least a code of conduct of some form that will prescribe the duties of advocates in the performance of their services as advocates and that there be some sort of disciplinary or other mechanism available to enforce that code of conduct.

Those are our main points. I will just summarize by repeating that we do endorse the legislation and would ask for it to be enacted and proclaimed as quickly as possible.

**The Chair:** Thank you. Each caucus has about four minutes for questions and comments.

**Mrs Sullivan:** I want to congratulate you, Mr Cornwall, on a very extensive and I think useful piece of work

in your recommendations. We have heard from other groups and organizations similar concerns; I think of research as being one area. The very practical work you have done even in bringing forward potential drafting changes is useful.

There was one area that really quite struck me as an interesting one and I thought you might want to expand on it. I have lost it now, but basically it relates to a patient being able to seek other treatment or to ask for specific treatment other than that which is recommended or put forward. I think it is in the definition of "consent."

**Mr Cornwall:** Yes. The point we have tried to make on that issue is that many people with AIDS and HIV rely upon alternative therapies and drugs and treatments that are not prescribed or not yet approved by law for treatment. They rely upon those substances.

The HIV community is constantly fighting for quicker access to a broader range of those treatments and our general concern is that we want our substitute decision-makers to be able to access them just as we ourselves could if we were in a situation of not being able to make requests ourselves. Until the absolute right to access such treatments is put into law, people with HIV and AIDS will continue to be using experimental sources to access drugs. We do not want that to be limited in any way simply because one has to use a substitute decision-maker to access a substance.

I cannot overemphasize the importance of these experimental drugs. They are very heavily relied upon, particularly because of the fact that this disease and its many opportunistic infections are new in the past 10 years and there are more and more drugs becoming available but the drug approval process is very slow. Is that the point you were asking about?

**Mrs Sullivan:** Yes, and I wanted to be certain that was on the record.

The other area I wanted to ask about, because it has created problems for many other groups, is your inclusion, in the definition of "treatment," of diagnosis. What health professionals tell us is that the inclusion of diagnosis in the definition of "treatment" means they cannot proceed even in an emergency situation to deal with caring for the patient if diagnosis is included. You could not even put a stethoscope on a chest, by example.

I am not asking you for a quick answer, but I think it would be useful if you put your mind to that, because I understand the difficulty with the use of the word "diagnosis" in HIV testing versus the use of the word "diagnosis" in other circumstances.

**Mr Cornwall:** I understand your question. There are two points. One is that we do believe that diagnostic processes should be included in the treatment, particularly because diagnosis and monitoring play a very significant role in monitoring the progress of the disease. Not a lot is known about the progress of the disease at this point. However, there are certain indicators that individuals can follow with the help of their doctors, and the availability of those diagnostic tests must be brought to the attention of

the infected individuals if they are to be properly monitoring their health care.

For instance, there are a series of blood tests that are available to monitor the cells of the immune system which are destroyed by the HIV virus and one can—this is a very sloppy description of it—monitor the rate of deterioration of the immune system by performing those diagnostic tests. We believe it is imperative that doctors be fully informed and that their patients be fully informed as to the availability of various tests so that they can properly monitor the progress of their disease.

That is important with respect to various treatments and prophylactic agents that can be used at various points in the progress of the disease. For instance, if somebody is reaching a certain level of deterioration of their immune system, they can start to take a particular series of drugs to prophylax against a form of pneumonia called PCP. In the early days of this disease many people died of PCP. Nowadays very few people do.

A second point on that is that the removal of diagnostic types of procedures from the definition of "treatment" is not necessary, in our view, because there continues to be a safeguard for practitioners in the legislation which permits them to rely on good faith on what they have done.

That is sort of off the top of my head, but I believe there should be some limitation on how far a health practitioner has to go. Obviously you do not have to go into a 6,000-page diatribe to explain every single available remedy, but there has to be a standard of reasonableness of some sort. But in our view the removal of "diagnostic" or "diagnosis" from the definition of "treatment" is not the way to accomplish that.

**Mr J. Wilson:** Thank you, Mr Cornwall. As Mrs Sullivan said, it is an excellent brief. I had stopped also, although I read through it, to underline the section where you refer to the definition of "treatment." I had to read it about three times to understand what it was you were getting at here in terms of life insurance policies. What I understand is you do not want the same definition of "treatment" used by life insurance companies, which would act as another discriminatory agent, in life insurance policies.

1540

**Mr Cornwall:** Yes.

**Mr J. Wilson:** As you know, our Progressive Conservative caucus did put forward a definition of "treatment" which would effectively exclude the diagnostic act and therefore amend what is in the legislation. Have you given any thought outside of your group, though, to how this might affect other individuals who may be deemed to be incompetent appearing in an emergency room? Our worry was that if a physician, and even the attending nurses, are not able to do some basic diagnostic procedures, there could be a real delay in necessary treatment, because medical physicians and a number of medical practitioners have said to us that often it is not easy to determine internal bleeding. We also have a concern with ambulance attendants who have to do some diagnostic work in order to stabilize a patient and transport him to hospital. That was the basis of our amendment.

I understand it in the case of AIDS and HIV. I think your concern there is more confidentiality and intrusiveness, is it not; that they would go ahead and perhaps do an HIV test without the consent of the patient? Maybe you could just comment on that.

**Mr Cornwall:** To answer your question, we should probably take some time to consider what you are saying to respond to it, but generally I would think that some sort of provision for emergency situations—

**Mr J. Wilson:** There is a provision in there, but many health care practitioners have said it just does not make any sense. If there is deemed to be imminent danger within 12 hours, then that is deemed to be an emergency, but it seems to be an arbitrary figure and there is a lot of difficulty around that clause too.

**Mr Cornwall:** That may be the case. However, I still do not think you should generally eliminate diagnosis from treatment because diagnosis is very clearly an element of treatment and needs to remain so and is part of something that people should be informed about. Decisions around diagnostic procedures should be left to the individual, after having been fully informed of risks etc.

**Mr J. Wilson:** Just so you understand, our amendment is really intended to deal with any delay that may occur in that process.

**Mr Fletcher:** Just a couple of comments and questions: One is that we have been sitting through these hearings over the past few weeks and it seems that the big-money professional medical people, the psychiatrists, the Ontario Medical Association and everyone else, are lined up on one side saying: "This is lousy. It's no good. We don't want it." Yet the community-based groups, such as your group, are coming in and saying, "It's about time; we need it." I was trying to get a grasp of why this is happening. I cannot really understand it. I could ask why that would happen, why they would do that. Do you have any—

**Mr J. Wilson:** There is a 19-page submission on amendments.

**Mr Fletcher:** I was just wondering if you have any comments on that or if you can understand that yourself.

**Mr Cornwall:** I really do not understand your question. Why what is happening?

**Mr Fletcher:** As I said, the professionals are lining up on one side opposed to advocacy legislation and everything else, and why the community-based groups are—

**Mr J. Wilson:** It is not that black and white.

**Mr Cornwall:** That probably has a lot to do, in our view, with the health practitioner profession wanting to maintain a high degree of autonomy.

**Mr Fletcher:** Protecting their turf.

**Mr Cornwall:** Basically, yes.

**Mr Fletcher:** How long has your organization been wanting legislation such as this?

**Mr Cornwall:** We have participated in the advocacy coalition activities for the past couple of years. I am personally not aware of prior to that.

**Mr Fletcher:** It has been a few years, at least, that you have been waiting for it.

**Mr Cornwall:** Yes.

**Mr Fletcher:** Are delays in the legislation going to help you or hinder you? This is something you have wanted. Do we do it now or do we just scrap it, as other parties are saying?

**Mr Cornwall:** Our position has been that although there are some minor problems with it, we agree with the Ontario Advocacy Coalition submissions. We could sit and talk about this for another five years, as governments are known to do with many different types of legislation.

**Mr Fletcher:** Previous governments.

**Mr J. Wilson:** This is the first time we have got into the nitty-gritty of legislation. Let's not mislead people.

**Mr Fletcher:** I am just asking the question, do we wait?

**Mr Cornwall:** To get right to the point, yes, there are many people in the HIV and AIDS community who will benefit from this legislation being enacted as quickly as possible.

**Mr Winninger:** Briefly in reference to the definition of "partner," I think a very compelling argument has been made that we should delete the reference to the recognition by others. What I would like to ask you about is the role of cohabitation. Let's take, for instance, partners who are not spouses. Do you feel that cohabitation should be a requirement in order to qualify as a partner to make these kinds of decisions?

**Mr Cornwall:** It is difficult for me to say strongly that is the case. There have been many groups and participants in our organization who believe it should be removed, but that was not a point we could come to a consensus on, asking for the removal of the cohabitation requirement.

**Mr Winninger:** The reason I ask is that you ask that the priorities be adjusted to put a partner who is cohabiting with the vulnerable individual ahead of a spouse who may not be cohabiting.

**Mr Cornwall:** Yes.

**Mr Winninger:** Would you agree with me there may be situations where one spouse, for example, is in a nursing home or a hospital of some kind and that is the reason they are separated, and it would still make sense for one spouse to be making personal care decisions on behalf of another, notwithstanding that they are separated?

**Mr Cornwall:** Yes, I agree. There could be situations like that.

**Mr Winninger:** Last then, do you think there should be a different test for partners versus spouses in terms of cohabitation, or do you think the same criterion should apply?

**Mr Cornwall:** Actually, just on your last point as well, my understanding is that the definition of "partner" requires that they be in a relationship of primary importance. I think that would probably be addressed by the fact that the spouse was in, for instance, the institution and is not actually cohabiting with the person any longer. The fact would remain that they have lived together and the

relationship is one of primary importance. Perhaps that person would be a partner as well as a spouse. I am sorry, I did not catch your next question because I was thinking of it.

**Mr Winninger:** I was just wondering, if you did agree cohabitation was an important criterion, whether that should apply to spouses as well as partners, because I can see situations where spouses may be living separate and apart under the same roof, or in some cases in different wings of the palace, and to draw the assumption that there is an ongoing meaningful relationship may be misleading.

**Mr Cornwall:** Yes. I generally agree with that.

**Mr Poirier:** I just want to tell both of you that I have had somebody very close to me die very recently of AIDS where the partner of that person was the first one to go to the medical authorities before that person died and was able to get all the information, saying, "I'm the partner of the person who is in hospital," whereas the family, that has been very supportive of the person who died with AIDS, was not able to get any information because, "Hey, we already have somebody who is a representative, a guardian of that person," who has died. He was in hospital at that point, and the family was not able to get anything.

There has to be something wrong somewhere. If the family is supportive and whatever, why the hell could they not get that information also? They had to go to the partner of the person who was hospitalized to get any information because the medical authorities would not even talk to the parents and the family. How would you respond to that?

**Mr Cornwall:** I would respond by saying that I think it would depend entirely upon the wishes of the person who was in the hospital and what he or she wanted. I would hope in that situation that the doctors and hospital staff would ascertain those wishes and that the partner would be well aware of those wishes and that if there was a reason for resistance with the family, that it would be justified, but it would depend entirely upon the wishes of the person.

1550

**The Chair:** Mr Cornwall, on behalf of the committee I would like to thank you for coming and giving us your presentation today.

**Mrs Sullivan:** On a point of order, Mr Chair: Mr Fletcher put some remarks on the record that it seems to me demean or attribute to the opposition motives that are quite different from what the motives are in our continuing opposition to these bills. We want, and I believe all of the intervenors who have appeared before the committee want, the best legislation to meet the principles that are being put forward. I think that while Mr Fletcher may not have understood that, the parliamentary assistants who have been participating on the committee are quite clear about that. I hope all the intervenors are as well.

**The Chair:** Thank you for that information.

**Mr Fletcher:** Is that a point of order?

## SCHEDULING OF PRESENTERS

**Mr Malkowski:** We agreed to send a letter to the institution to allow two presenters to come to the committee. Could I ask the clerk if the letters have been sent, or the one letter, to Mimico and the other facility, and what happened?

**Clerk of the Committee:** Two letters were sent. The response from both institutions was negative. At this point we are still dealing with one individual to see whether we will be arranging a teleconferencing for tomorrow.

**Mr Fletcher:** A point of order, Mr Chair.

**The Chair:** One moment, please.

**Mr Malkowski:** As a follow-up to that, the other institution said no. Was there any reason given? Was it with no explanation or with an explanation?

**Clerk of the Committee:** There were no explanations from either institution.

**Mr Malkowski:** I think it is important that we follow up on that issue.

**The Chair:** What kind of follow-up would you recommend?

**Mr Malkowski:** I would recommend that a person perhaps needs to get a temporary pass to allow him to come and present. Which institution said no?

**The Chair:** Both.

**Mr Malkowski:** Was it the review board that said no or was it the superintendent? Could you clarify that for me, please?

**Clerk of the Committee:** The letter to Mimico went to the superintendent of Mimico, and the letter to Kingston Psychiatric Hospital went to the doctor I was dealing with who had authority over the patient to either allow him out or not allow him out.

**Mr Malkowski:** So the superintendent was the one who said no.

**Clerk of the Committee:** Actually, I am not sure, because the phone call did not come back from the superintendent; the phone call came back from somebody else at Mimico relaying the information that they would not provide a day pass.

**Mr Malkowski:** I think it is important that we perhaps send another letter to emphasize the invitation for this person to come to the committee.

**The Chair:** I think one of the problems we are dealing with right now is that tomorrow is the last day of public hearings. To send a letter would be fruitless at this point. There was one announcement I was going to make, that if we can set up the teleconferencing tomorrow, it would be at 1:30. That is the only time room 151 is available. We are still waiting for a response on that.

**Mr Fletcher:** On a point of order, Mr Chair: Did you rule on that point of order from Mrs Sullivan?

**Mrs Sullivan:** Yes, he said I was in order and that I was right.

**Mr Fletcher:** No, he did not.

**The Chair:** If you did impute motives, then yes, she did have a point of order.

**Mr Fletcher:** Did I impute motives?

**The Chair:** I would have to check the transcript on that.

**Mr Fletcher:** Thank you, Mr Chair.

**Mr J. Wilson:** Mr Chairman, I just have a point of information. At 9 o'clock tonight on PBS—I think that is channel 18 on our cable in Toronto—is the case of Nancy Cruzan, who was the lady in the United States, I believe, who for some 10 years was in a coma and the family was involved. There is a very moving program on tonight that members may want to watch. It deals with the government's intervention into the decisions made by the family.

**Mr Winninger:** Is this the Quinlan matter?

**Mr Fletcher:** No, that was another one.

**Mr J. Wilson:** I think Nancy Cruzan is the one I saw. It is a different case than the Karen Ann Quinlan case.

**The Chair:** For the information of the committee, the library will be taping it, so it will be available to the members. Thank you for that information.

Anything further? Seeing nothing further before the committee today, this committee stands adjourned until 10 o'clock tomorrow morning.

The committee adjourned at 1555.

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## Legislative Assembly of Ontario

First Intercession, 35th Parliament

## Official Report of Debates (Hansard)

Wednesday 25 March 1992

### Standing committee on administration of justice

Advocacy Act, 1992,  
and companion legislation

Chair: Mike Cooper  
Clerk: Lisa Freedman

## Assemblée législative de l'Ontario

Première intersession, 35<sup>e</sup> législature

## Journal des débats (Hansard)

Le mercredi 25 mars 1992

### Comité permanent de l'administration de la justice

Loi de 1992 sur l'intervention  
et les projets de loi  
qui l'accompagnent

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Greffière : Lisa Freedman

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# LEGISLATIVE ASSEMBLY OF ONTARIO

## STANDING COMMITTEE ON ADMINISTRATION OF JUSTICE

Wednesday 25 March 1992

The committee met at 1008 in committee room 1.

### ADVOCACY ACT, 1992, AND COMPANION LEGISLATION

### LOI DE 1992 SUR L'INTERVENTION ET LES PROJETS DE LOI QUI L'ACCOMPAGNENT

Resuming consideration of Bill 7, An Act to amend the Powers of Attorney Act; Bill 8, An Act respecting Natural Death; Bill 74, An Act respecting the Provision of Advocacy Services to Vulnerable Persons / Projet de loi 74, Loi concernant la prestation de services d'intervenants en faveur des personnes vulnérables; Bill 108, An Act to provide for the making of Decisions on behalf of Adults concerning the Management of their Property and concerning their Personal Care / Projet de loi 108, Loi prévoyant la prise de décisions au nom d'adultes en ce qui concerne la gestion de leurs biens et le soin de leur personne; Bill 109, An Act respecting Consent to Treatment / Projet de loi 109, Loi concernant le consentement au traitement; and Bill 110, An Act to amend certain Statutes of Ontario consequent upon the enactment of the Consent to Treatment Act, 1992 and the Substitute Decisions Act, 1992 / Projet de loi 110, Loi modifiant certaines lois de l'Ontario par suite de l'adoption de la Loi de 1992 sur le consentement au traitement et de la Loi de 1992 sur la prise de décisions au nom d'autrui.

### NATIONAL ASSOCIATION OF WOMEN AND THE LAW

**The Chair:** I call this meeting of the standing committee on administration of justice to order. I would like to welcome our first presenters from the National Association of Women and the Law. Good morning. Just as a reminder, you will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are ready, could you please identify yourself for the record and then proceed.

**Ms Stoltz:** Good morning. Thank you very much to members of the standing committee on administration of justice for extending to us the opportunity to appear this morning and present our written and oral submissions on the government's proposed legislative package regarding consent to medical treatment.

My name is Lori Stoltz. I am a litigation lawyer with the firm of Goodman and Carr in Toronto. I am a specialist in health litigation. With me this morning is Freya Kristjanson, a litigation lawyer with the Toronto firm of Borden and Elliot. Ms Kristjanson is a specialist in constitutional litigation. Ms Kristjanson and I are co-chairs of the reproductive and health issues working group of the National Association of Women and the Law.

The National Association of Women and the Law is a national, non-profit, feminist organization active in legal research, law reform and public legal education. NAWL's membership is composed of lawyers, academics, students and related professionals. The reproductive rights working group has taken a strong and consistent stand in favour of women's reproductive rights including, in particular, the right of women to abortion. We made oral and written submissions to the Law Reform Commission of Canada on its working paper, Crimes Against the Foetus, to the House of Commons committee on Bill C-43, An Act respecting abortion, and to the standing Senate committee on legal and constitutional affairs dealing with Bill C-43, An Act respecting abortion.

First and foremost, NAWL would like to express its support for the general principles endorsed by the government in Bills 74, 108, 109 and 110. Having said that, the focus of our comments this morning will be upon those aspects of the proposed legislative package we would like to see altered before these bills are presented to the Legislature for third and final reading.

Copies of our written brief have been provided to you. It is the turquoise brief that has been circulated. Our presentation this morning will take the following form: I will deal with the right of pregnant women to consent to medical treatment and then address briefly the need to ensure uniform access of all patients to their medical records. Ms Kristjanson will then deal with access to reproductive counselling and services for persons under 16 and will make some general comments about the legislative package.

Bill 109 does not directly address the capacity of pregnant women to give or withhold their consent to medical treatment on their own behalf or on behalf of the fetuses they carry. Bill 8, however, purports to derogate from their capacity and right to do so by providing expressly in subsection 3(3) that, "The living will of a person is not valid while the person is pregnant."

In a series of recent decisions, including Morgentaler, Daigle, and Sullivan and LeMay, the Supreme Court of Canada has firmly established that a foetus is not a person at law, that the foetus does not have a right to life and that a pregnant woman may abort the foetus she carries independent of the wishes of the foetus's biological father. Therefore, although the issue has not come before the Supreme Court of Canada directly, NAWL submits that the cumulative effect of these decisions is to support the right of pregnant women to accept or to reject a proposed course of medical treatment on their own behalf and on behalf of their fetuses.

Despite the clarity of these judicial precedents from our highest courts, however, the absence of an unambiguous statement of this right by the Legislature troubles physicians and leaves them uncertain of their legal

responsibilities and potential liability. This uncertainty recently prompted the committee on ethics of the Canadian Medical Association to develop a discussion paper which recognized the human foetus as the "ethical equal" of its mother at approximately 23 weeks' gestation and encouraged physicians to invoke a legal process to determine whether the clearly expressed wishes of a pregnant woman with respect to her own treatment or the treatment of her foetus might be overridden. This uncertainty also prompted the Ontario branch of the Canadian Bar Association, in the written submissions it prepared for this committee, to ask questions such as:

"Will the unborn have recognizable rights? If a patient refusing or requesting treatment is pregnant, will it be necessary to obtain the consent of the official guardian on behalf of the unborn? Will a father have specific rights to consent on behalf of the unborn in these circumstances?"

Similarly, in its working paper, *Crimes Against the Foetus*, the Law Reform Commission of Canada recommended the enactment of legislation that in our view would impose criminal sanctions upon women whose conduct during pregnancy may be linked to a developmental abnormality in their foetus and would also likely authorize the imposition of court-ordered medical treatment upon pregnant women, including diagnostic procedures such as amniocentesis, Caesarean section deliveries and possibly foetal surgery, where consent to that treatment is withheld by the pregnant woman.

Finally, a series of lower court decisions in Ontario as well as a number of recent American court decisions demonstrate the willingness of some courts, given the opportunity, to evade judicial precedents, no matter how strong or how clear, in favour of their personal prejudices, to the detriment of pregnant women.

A Belleville woman, for example, was assessed under Ontario's Mental Health Act on the order of a court that declared her foetus a child in need of protection and sought to control her physical person to protect that foetus. This order could have culminated in the woman's commitment to a psychiatric facility as an involuntary patient, a complete and horrifying deprivation of her liberty and autonomy.

Similarly, in a recent American case a court ordered a young woman in her 26th week of pregnancy and dying of cancer to submit to a Caesarean section delivery of the foetus against her clearly expressed wishes. In the words of the court that made this order, "Although the chances that this foetus would survive were slim, the woman herself had at best only two days to live." It is also worth noting that despite this woman's clear instructions from the beginning of her pregnancy that she be kept as comfortable as possible during her pregnancy, regardless of the possible effects upon the foetus, chemotherapy recommended for her by her cancer specialist was withheld from her by other treating physicians on the grounds that it posed too great a risk of harm to the developing foetus.

It is clear, given the position papers and the judicial decisions I have just canvassed, that although many pregnant women in Ontario do not have physical or mental impairments that would identify them as vulnerable adults as that term has been used by the government in identify-

ing the aims and objectives of this legislative package, there is no question in our minds that pregnant women are vulnerable adults in the context of the health care system.

Decisions like these should not be left to judicial discretion and courtrooms are not the place to make them. However, nothing less than a clear statement by this government and this Legislature affirming the right of pregnant women to give or to withhold their consent to treatment on their own behalf or on behalf of the foetuses they carry will eliminate the problem. I would like to point out that this statement we are making is consistent with section 14 of Bill 109, which enumerates the principles that should guide decision-making on behalf of incapable persons. There is nothing in this section that would lead one to believe the interests of the foetus should be at all considered. Accordingly, NAWL urges the Minister of Health to give effect to her stated commitment to the inviolability of the right of pregnant women to autonomy, dignity and freedom by adopting the following recommendations.

1. Bill 8 should be amended to exclude subsection 3(3).

2. Bill 109 should be amended to include a provision which expressly recognizes the capacity of pregnant women to give or to withhold their consent to medical treatment on behalf of their foetuses.

3. Bill 109 should be amended to include a provision which states expressly that the fact that a woman is pregnant will not derogate from her right to give or withhold consent to her own medical treatment.

4. Bill 108 should be amended to include a provision which allows an attorney for personal care or a guardian to withdraw from the treatment decision-making process temporarily; that is, without terminating the guardianship or the power of attorney, should he or she be called upon to consider the appropriateness of a treatment or a course of treatment which raises the potential for conflict with strongly held personal or religious beliefs on the part of the guardian or the attorney.

With respect to the question of uniform access of patients to medical records, it should be said that access to one's own medical records is a critical element of one's right to exercise informed consent to medical treatment. Under the current legal regime, however, the rights of patients to examine and copy their own medical records depend upon the context in which the records are created and held, in much the same way as other aspects of consent to health services vary with the health care service and the setting in question.

Unfortunately, Bills 74, 108, 109 and 110, as currently drafted, do not address this problem in any comprehensive way. If anything, they leave patients' rights of access even more uneven than before. Subsection 37(2) of Bill 109, for example, extends to patients the right to examine and copy any medical or other health record but only in the context of a hearing before the Consent and Capacity Review Board. Similarly, section 24 of Bill 74 allows advocates, with the consent of the vulnerable person to whom the information relates, "access...to any record relating to the person that is in custody or control of a facility." This provision has two shortcomings: (1) Access is limited to

the advocates of vulnerable persons rather than the persons or patients themselves and (2) the word "facility" is left undefined, leaving it unclear as to whether the medical records of physicians held in their private offices are encompassed by this provision. Patients who do not fall within the scope of either of these provisions are left to the vagaries of the current patchwork of legislation governing the disclosure of medical health records by health care professionals, hospitals and psychiatric facilities, and these are uneven.

Our recommendation, then, is that Bill 109 be amended to include a provision which extends to all patients the right to examine and copy all medical records, including clinical notes, charts and all other material relating to patient care, regardless of where those records are held, subject only, and only if necessary, to the provisions of the Mental Health Act of Ontario.

Thank you. I will now pass the floor to Ms Kristjanson.

**Ms Kristjanson:** I will be addressing two issues. The first is the access to reproductive health services on the part of individuals who are less than 16 years of age. Second, I will be making some general comments regarding the structure of the system.

I note that the Progressive Conservatives have introduced a motion to amend Bill 109 by striking out section 8, which you will find is the recommendation we have also made. I understand you have probably heard a number of submissions on the age question, so I will be very brief.

1020

**Mr Poirier:** A very long list.

**Ms Kristjanson:** Oh, you have. Okay. I think I will talk a little bit about the question of delay and access to abortion services. Our other concerns are set out in our brief.

The Supreme Court of Canada, in the Morgentaler decision, struck down abortion provisions of the Criminal Code in part because the court found that state-imposed administrative delay violates a woman's right to life, liberty and security of the person under the Canadian Charter of Rights and Freedoms. The state-imposed administrative delay in that case was a therapeutic abortion system. We are concerned, however, that a young person who has been found incapable by the physician and therefore must resort to the advocacy and board review systems could similarly encounter delay.

We draw your attention to the words of then Chief Justice Dickson in the Morgentaler decision, who said that in the context of abortion, any unnecessary delay can have profound consequences on a woman's physical and emotional wellbeing. We would prefer, as the Progressive Conservatives have suggested, that the whole question of incapacity and age be left with a standard that is similar to the common law, that is, that would allow a physician to make a determination if an individual understands the nature, purposes and consequences of treatment.

Turning to more general comments, we note that in introducing the bills in the Legislature the Attorney General stated that linking all of these complementary legislative reforms are the themes of liberty, empowerment,

self-determination and the right to make choices. As a feminist organization, the National Association of Women and the Law is dedicated to the empowerment of women, the right of women to self-determination and autonomy and the right to make choices. We thus support the avowed goal of the legislation, respect for autonomy.

We are, however, deeply concerned by some of the provisions of these statutes. At a time when women's health care needs are not being met, amid increasing demands for a variety of government services to address issues concerning violence against women, women in poverty, immigrant women and others, we believe that the creation of such a costly, complicated and administratively complex system may be an excessive response.

Another concern relates to the fact that it is primarily women who are care givers for many of the individuals who may become subject to the system. It is most often women who make decisions and care for elderly relatives, vulnerable children and spouses. For this reason, we have drawn your attention in the brief to some of the cumbersome and complex provisions of Bill 108 which we feel will create a very difficult system for women who are caught up in it.

We are also concerned with some of the provisions of Bill 109. While the rights of vulnerable persons may be subject to abuse, and we acknowledge that, we are concerned with the assumptions which seem to underlie both the advocacy and the consent systems. These systems seem to presume that family members and health care providers cannot be trusted to make decisions or to assist in decisions for vulnerable persons. We are not necessarily persuaded that this is the case.

A further concern related to that which I just mentioned is the role of advocates within the system, and the qualifications. We are concerned that in providing strangers with such a crucial role, we run the risk of replacing one relationship of dependency—dependency on the family, dependency on the health care professions—with another. This new dependency relationship is then institutionalized.

Existing social institutions and the role of the caring professions are being displaced, and there is no guarantee, nor any experience, with the adequacy of the services which will be provided. We must always remember that the state is not necessarily benevolent; nor will representatives of vulnerable persons always act in the best interests of the patient. We draw your attention to a particular conflict, for example, a Catholic advocate called in to consult with respect to an abortion decision. We are concerned that these conflicts will not necessarily be appropriately resolved and, given the breadth of the system, it will be very difficult to determine where the fracture points might come.

As you know, there has been an intense discussion within the various communities affected by this bill: communities of women, communities of health care providers, health care consumers, lesbian and gay organizations, physically and mentally disabled communities. There are many strands of criticism. For many, the system appears to be one which will finally put into effect adequate state administrative and legislative protection for vulnerable persons. For others, the system appears to be an unjustifiable

intrusion into the structure of the family, the health professions and existing health care institutions.

Nearly all are concerned with the cost to the health care system at a time of diminishing resources and increasing demands for social and economic programs. Given the depth of these concerns and the massive changes contemplated by these bills, we suggest that a pilot or demonstration project might be the best way in which to determine, for all involved, whether or not this is an appropriate system.

We draw support for this recommendation from the Inquiry on Mental Competency: Final Report, the Weisstub committee, which recommended that pilot studies be supported to identify the most effective and efficient method for implementing recommendations. The committee recommended that pilot studies be conducted in a variety of settings such as psychiatric and general hospitals, geriatric and children's facilities and community and health centres. They noted that when evaluating models for the implementation of recommendations, it is necessary to consider the relationship between capacity and support structures, both institutional and non-institutional, in the community. That is a particular concern here because I know many of the presenters have emphasized that they feel existing institutional and non-institutional support structures are being displaced, and we do not know what will be replacing this.

The implementation of a pilot study could be effected in a manner similar to that which was accomplished with the Intervenor Funding Project Act, which simply had a provision in there stating that the purpose of the act is to provide for the establishment and conduct of a pilot project. Indeed that has been carried out. The case management system, which affects the conduct of civil cases, is another example of where effective pilot studies were used. Legislation was subsequently changed and the system has generally worked much better.

Given the extreme depth of concern, this will be the best method by which to determine whether or not the worst fears of the critics of this system are borne out, whether the administrative costs are so prohibitive and the degree of intrusiveness into the functioning of health care institutions and other social institutions are so deleterious that the systems must be revamped. Conversely, the degree to which individual self-determination and autonomy is better respected, assisted and supported under this new system could be assessed and critics satisfied.

We thank you very much. We would be happy to entertain any questions you might have.

**Mr Poirier:** I feel very comfortable with your presentation, though I am not a Tory, although I am dressed in blue like heck today, and so are you. A pilot project is fine in principle, and I can understand where you are coming from and what you want to do. I do not know how much you have followed presentations that have been made before us similar to yours, but you are not alone, believe me, especially with the aspect of age. A lot of the health care practitioners who have come forward think the theory is okay but the practical application is completely out to lunch.

I am a strong adept of pilot projects in principle, but with such a loose cannon, even as a pilot project, it would seem that we would be wasting a lot of people's time. I think there is a lot of major surgery to be done in the bills before we would even want to consider a pilot project, which would be a good idea. How do you feel about this? Do you honestly think the bills are ready to go for pilot projects right now? If I were a doctor or a nurse and my hospital had been chosen as a pilot project, I would really be having a— I do not know what.

1030

**Ms Kristjanson:** We are aware. We have not done a detailed section-by-section analysis. We certainly have read the extensive criticisms which have been made. Many of those are legal drafting concerns, many others go to the very heart of what the government is attempting to do. The reason we have suggested a pilot project is that it is our understanding the government is intent on enacting this system. We are also very sensitive, as lawyers who work doing health and constitutional litigation, to the concerns of health care professionals.

**Mr Poirier:** Of course.

**Ms Kristjanson:** Therefore, we suggest that if the government is indeed intent on establishing the consent in advocacy systems, the goals of which we applaud but the details of which we are unsure, it should best be done on a limited scale because of the potential to completely disrupt the health care system and drain away necessary dollars.

**Ms Stoltz:** I think we are comfortable with the legislation going forward as it stands now on a pilot project basis.

**Mr Poirier:** You are sure about that?

**Ms Stoltz:** Yes.

**Mr Poirier:** It surprises me actually that you come out with that because health care practitioners, in the practical application, just do not think, even though they support the principle—I would not want my hospital to be chosen for a pilot project right now the way it is written.

**Ms Stoltz:** Right now you have a proposed system to work with and it all fits together very nicely. I think what you have to do is to put it in practise to see whether the problems do crop up the way the health care providers say they will. I think it is something they can work with and should be permitted to provide some impact on once they have practical experience with it.

**Mr Poirier:** Unfortunately if some individuals end up being the victims of the screwy things in the pilot project, and if one of those victims happens to die and is close to you, you might want to come forward after and say, "There is a hell of a cost that can be added to a pilot project when there are so many things that can go wrong." If one of the persons close to you is the victim and dies because of something wrong in the pilot project, I think it would add a very different coloration to what you just said. You may want to think about that one.

**Mr Sterling:** Our party has tried to work as constructively as we can with these bills because we realize that the issues here are not without merit. In other words, there are vulnerable people in this province and there is a problem

in terms of consent issues that exists in the common law and statute law we presently have. We would like to work towards a solution, so we do not dismiss your pilot project idea out of hand and think it probably has some merit.

As people who advocate for a select group in society, are you—my concern with the Advocacy Commission, and it has been expressed in this room on a number of occasions, is that when you put advocates out there for a group of people and you have very little framework around which they are operating, there are a number of concerns you have: number one, what motivates the system? Is it the individual, the vulnerable adult, or is it the partisan commission that is being set up under this legislation? The advocacy groups that have come in front of this committee have told us they are going to be partisan.

Is the advocate or the Advocacy Commission going to act for general goals, or are they going to act for the good of the vulnerable adult in this specific instance? You strike here as well a problem I see in terms of the individual advocate who might believe very strongly in a moral sense that he or she should stress one point or another because of his own moral or religious or social goals.

We are going through this in terms of the legal aid system in our province at the present time. There is sort of a veiled threat that there is going to be a public defender system. I have very great concerns about a public defender system, because then you start to get a whole bunch of other things that are there that are driving the system etc. Do you think an Advocacy Commission, which is going to be starkly partisan, without guidelines, with tremendous power and seemingly unlimited financial resources, because I do not think any government could resist the commission in terms of providing it with substantial dollars, is the right way to go?

**Ms Stoltz:** We share with you your concern about what is motivating the system, and I think that is what Ms Kristjanson was trying to get at when she talked about the problem of substituting one relationship of dependence for another. What is motivating the creation of this system, it appears to me, is the recognition that there are vulnerable adults in our society who are not properly cared for in the health care context. The question is, what is the appropriate thing to do here? It seems to me that what has been left out is the whole question of education of health care practitioners to be more sensitive to the needs of the people who are within their care.

I think it has to be said that while this is a system that addresses one relationship in which there is clearly a power imbalance in that the health care provider has more power and knowledge, generally speaking, than the person who is under his care, in substituting this person for an advocate you again have a power imbalance, and there are problems in personal relationships that you simply cannot control.

One of the things we are quite concerned about is something you hit on, and that is the possibility that you may have advocates who are motivated by strongly held personal and religious beliefs who will allow those to intrude on their function, which I understand to be simply

helping vulnerable persons advocate their needs and their wishes. So yes, it is an area of concern to us.

**Mr Sterling:** We have heard—

**The Chair:** Thank you, Mr Sterling.

**Mr Sterling:** Could I just have one supplementary?

**The Chair:** No. Thank you, Mr Sterling. Mr Winninger.

**Mr Winninger:** Unlike Mr Poirier, who seems to feel we are out to lunch, you have looked at the menu, and overall—

**Mr Poirier:** Respectfully.

**Mr Winninger:** Overall you seem to be happy with the direction we are moving in. There are some constructive suggestions you have made for changes. Mr Poirier, just because he does not like the menu, says we are out to lunch.

**Mr Poirier:** You do not have a good chef.

**Mr Winninger:** I would draw your attention to a couple of the comments you make in regard to Bill 108, in particular on page 6 where you suggest that our requirements for powers of attorney for personal care might be too rigorous, and you list some of the requirements, having two witnesses, validation and this sort of thing.

As practising lawyers, I am sure you are aware that we have safeguards when it comes to last wills and testaments, and surely there should be the same kind of safeguards in place for personal care that there are after you die. It would seem to me that the kinds of requirements we have included in the legislation would be the kinds of minimal requirements one would expect to be there if one is to rely on an instrument that is going to create such far-reaching powers. It would even extend, as you seem to indicate, to the right of a woman to make decisions over the future of a foetus. Perhaps you could comment on that.

**Ms Kristjanson:** Certainly. I think our concern relates to the fact that this system is institutionalizing and over-legalizing almost all relationships between individuals once they enter the health care system. I agree with you that there are necessary legal requirements and formalities when executing a will, for example, because we want to be absolutely sure that something is correctly followed. I think our concern is because the resort to substitute decision-makers will now be much more prevalent in the system. It will be a tremendous work generator for Ms Stoltz and myself, because it appears to us that people will be running off to lawyers at the drop of a hat whenever a call for care is made, and we think that is an overformalization, an overlegalization, of many issues.

I think that when we look at some of the provisions, in some contexts they are necessary, but we fear that the system is overinclusive. It extends into too many situations, and in some of those situations we believe that both for individuals who will be making decisions and for the health care providers who are trying to find someone who has that authority, this system is simply too complex. In some situations these safeguards are necessary; in others it is simply an overly complex and overly legalistic response to a problem. That is where that comes from.

1040

**Mr Winninger:** I guess you agree it depends on the kind of case.

**Ms Kristjanson:** Yes, we do, but we think, again, the legislation is not carefully tailored enough to distinguish between various kinds.

**Mr Winninger:** I see the Chair shaking his head.

**The Chair:** Thank you, Mr Winninger.

**Mr Winninger:** But I have just one quick point, and I think it is an important one. You suggest that there be a pilot study for all four pieces of legislation, and I would suggest to you that a pilot study would not make a lot of sense in terms of Bills 108 and 109.

**Ms Kristjanson:** I disagree completely on that.

**Mr Winninger:** Why would you want a pilot study on substitute decision-making in the sense of—

**The Chair:** Thank you, Mr Winninger.

**Ms Kristjanson:** The substitute decision-making may be slightly different. The problem is that for most health care practitioners it is Bill 109 which is causing the greatest concern. You obviously have to have a pilot study of Bill 109 to see how it will function in a variety of institutional settings.

**The Chair:** Ms Stoltz, Ms Kristjanson, on behalf of the committee I would like to thank you for taking the time out this morning and coming and giving us your presentation.

BONNIE BURSTOW

**The Chair:** I would like to call forward our next presenter, Dr Bonnie Burstow.

**Dr Burstow:** I am Dr Bonnie Burstow. I was originally presenting solely on my own behalf, though at this point two groups have endorsed what I have said and asked me to speak on their behalf too, and those are Phoenix Rising and RAP, Resistance Against Psychiatry.

I am a supervisor of numerous therapists in the city. I am also somebody who used to be a full-time faculty member in the social work departments at Carleton University and the University of Manitoba. I am used to issues around care givers and also teaching around laws affecting care givers.

I think there are some problems with a number of the acts. The act I want to say least about is the Advocacy Act, because I see this as essentially a very good act. At the moment there is a petition being sent around the Ontario Public Service Employees Union suggesting that these advocates are not needed because public servants are already doing the advocacy. I would like to suggest that public servants are very often in an inherent conflict of interest with the people they are serving and that we very much need independent advocates.

Overall, one problem I have with the acts as a whole is that there are not clear avenues for enforcement. I would like to suggest in terms of the \$5,000, which is put out in two of the acts, that \$5,000 would not be much of an obstacle for a lot of people against violating conditions in an act. I would really like that reconsidered. Something like a third of their salary might be a much more sizeable

and meaningful obstacle. Something that specifies that no other body would reimburse them for this also might be helpful.

My main concern is with the Consent to Treatment Act, but I want to start with the Substitute Decisions Act. Section 56 allows the court to make an order for full guardianship of the person and then specifies in points (a) to (c) what a guardian cannot consent to against the person's wishes, and these are admitting the person to a mental institution against his will, change in custody relationships, or electroshock for the purpose of aversion conditioning. I would like to add a (d) and an (e). Point (d) would be consent to electroconvulsive therapy. We are looking at an inherently damaging form of "treatment" and I do not feel a guardian should be able to force this upon someone against his consent, and (e) would add consent to neuroleptics and anti-depressants against the person's wishes. Again, we are talking about drugs that can cause serious neurological problems, including tardive dyskinesia, which is irreversible, and a guardian should not have the power to impose these on a vulnerable person.

Section 63 itemizes things a guardian should not do, and in the process of doing that it looks at the fact that guardians may be able to restrain a person if he or she is causing bodily harm to another or himself. What I am going to say may be very difficult for people to follow here. I have absolutely no problem with a guardian being able to restrain a vulnerable person who is causing harm to someone else. I think we need to seriously modify the whole question of restraint when it comes to harming themselves, and let me explain why.

As a therapist in the city, I have worked and specialized for many years with women who self-mutilate themselves. I can tell you that a very high percentage of incest survivors regularly and routinely self-mutilate themselves and that this is a way of coping and getting by in the world. I do not suddenly want to see these people restrained. I have seen what happens when people try to stop them. Suddenly actions that are done in awareness become out of awareness and all sorts of things which are not desirable happen. I think we have to look very carefully at rewording this section.

Going on to the consent to treatment bill, section 5 reads, "Consent to treatment may be express or implied." I would like to suggest that this is extremely open-ended and that it invites abuse. I would like to have it read instead, "Except where a person is incapable of expression, only expressed consent is acceptable," and "Except where a person is incapable of writing, expressed consent must be in writing." That way we have more reason to believe real consent is happening and we are not simply having to take someone's word that when no one else was around, this person gave a nod.

Section 6 reads:

"(2) A person may be capable with respect to some treatments and incapable with respect to others.

"(3) A person may be incapable with respect to a treatment at one time and capable at another."

I have no doubt this is true. However, I think we again have a statement here that could be used in ways that are

quite abusive. We all know that it is very easy for a care giver to think the person is capable of consent to treatment when he gives consent, but incapable and not understanding it when he does not give consent. I think we need a further statement that, "If the treatment is a controversial one, such as psychiatric treatments are"—which is one example—"agreement or disagreement with the care giver's understanding of the treatment and need for it may in no way enter into any decision on the person's capability to decide on treatment." Otherwise, we open the door for very subjective decisions around capacity.

Section 13 reads, "Wishes with respect to treatment that a person expresses, orally or in writing, while capable, override earlier instructions with respect to treatment that are contained in a power of attorney."

Again, the person has gone to great effort to put something in a legal form and power of attorney. I do not want to see a situation—and this certainly opens the door to a situation—that the person says, "Do you want this treatment?" and the person kind of semi-nods and it says, "Oh, well, this person is now capable, and while capable they agreed to this treatment." Again, we would want something in writing so we knew it was being done in a deliberate way and this is really indeed what the person meant. I do not think we should be creating very carefully worded legal situations and then allow them to be brushed away this easily.

Section 29 deals with the possibility of a substitute decision-maker applying to the board for permission to give consent to a treatment despite instructions when capable to refuse such treatments. It reads,

"The board may give the applicant permission to consent to the treatment, despite the instructions or wishes, if it is satisfied that the incapable person would probably, if capable, give consent because the likely result of the treatment is significantly better than would have been the result of treatment that was available in comparable circumstances at the time the power of attorney was given or the wishes were expressed."

There are many situations where I can see the value of this concern. Somebody has AIDS and when he is competent he says, "I don't want this treatment," because he has all sorts of awful side-effects, his hair falls out etc. He becomes incompetent with respect to treatment and the drugs are seriously improved. They no longer have these complications, his hair does not fall out, he does not vomit every day. The substitute decision-maker really needs to be able to shift.

1050

We are in a very different situation with other categories; specifically, we are in a different situation when it comes to psychiatric drugs. We all know that almost every day psychiatrists are claiming, "We now have a great new improvement on this drug." We all know this is claimed. "These terrible side-effects that existed with the past drug do not exist now. These drugs are enormously good and are improved." These are common claims and we see them year in and year out.

For somebody who has made it clear that he or she does not want anti-depressants, does not want a souped-up

anti-depressant that is now being claimed as "way better," I am concerned that with this act it would be very easy to give them that.

I am asking for a change here. I am asking for the addition of the following sentence: "The board will not give such consent in the absence of indisputable proof that the incapable person suffers from a genuine physical disease"—and please note, there are no such proofs in psychiatric diseases—"and indisputable proof that the treatment in question addresses the physical disease." Again, this would be a way of leaving out the psychiatric treatments, which are controversial at best and where there is certainly no indisputable proof that they are addressing a bona fide physical illness in any way.

I would just like to make one further comment with respect to the previous submission in terms of the Advocacy Act. One of the speakers asked that not just the advocate but the incapable person, the vulnerable person, be able to examine and copy all records, subject to the provisions of the Mental Health Act. I would agree with that, leaving out the words, "subject to the provisions of the Mental Health Act." It is very important for people to know what is being written about them and on what grounds people are doing what, and it is not easy to get such information with the present Mental Health Act.

I have had clients who had to go through six lawyers before one of them was finally able to get the actual stuff. It is not easy. It would be, I think, a clear improvement if the advocate had the right and even the responsibility to provide the person with such information if the person wished it. The need for consent of the doctor is somewhat a joke, I think, seeing as the doctor is often the person who the vulnerable person is in conflict with. That is all I would like to say. I am open to questions.

**The Chair:** Thank you. We have time for about six minutes for each caucus. Mrs Sullivan.

**Mrs Sullivan:** Dr Burstow, I am very interested in your presentation and I wanted particularly to concentrate my questioning on the last point you made with respect to section 29 of Bill 109, which would enable a substitute decision-maker to apply for a change in the instructions. Do you ever see circumstances in the care of mentally incapable people where indeed there is proof of changed circumstances as a result of medical or other therapeutic treatment?

**Dr Burstow:** Certainly. A mentally incapable person could develop diabetes, which he did not have before, and I am saying that the change would in no way affect that.

**Mrs Sullivan:** Okay. Can I just rephrase that?

**Dr Burstow:** Yes.

**Mrs Sullivan:** Particularly in relationship to the mental condition.

**Dr Burstow:** The mental condition can change. We are still in a situation where there is no substantial proof that there is any physical disease present, and to be able to impose treatments like this against the patient's expressed wishes gives me great concern. Again, it opens up loopholes.

I have talked to many people about these acts, people who are in jeopardy, and they are very, very concerned. They are going to do their very best to stop having some treatment, and this section is going to make it possible for their wishes to be overridden. I do not want to see that happen. We are looking in terms of psychiatry at a whole area where people have historically been given things against their wishes, and I do not think we should pretend otherwise. It is very different than other areas of the health system where adversarial relationships are far less common. This is an area where adversarial relationships are very common and every effort is quite often taken to get around what the person actually wants.

**Mrs Sullivan:** For example, if there were changes in the treatment of Alzheimer's patients which contributed to substantial improvement in cognitive ability, would not your proposal for the addition that would limit consent to physical ends—

**Dr Burstow:** Can I answer that, because I understand your concern and, no, it would not affect it in any way. Alzheimer's is a physical condition that is physically verifiable. In fact, it would allow people to say, "On this physical condition which is physically verifiable," which Alzheimer's is. It is a brain disease. The brain is physical. One could go ahead and show that there was greatly improved treatment and there was reason to believe that this person would take it. I am talking about the mental illnesses which are not physical diseases but metaphors. With real physical diseases like Alzheimer's, there is no question that this is a physical disease and I am not trying to protect people against that kind of treatment.

**Mrs Sullivan:** Would you consider schizophrenia a physical disease?

**Dr Burstow:** I most certainly would not. Nor is there any scientific evidence to substantiate that it is a physical disease. In fact, the branch of medicine that deals with what is or is not a physical disease has never listed schizophrenia or any of these mental illnesses because the scientific proof is not there.

**Mr Sterling:** We are told that schizophrenic patients occupy approximately 50% of the hospital beds in our psychiatric institutions. We are told that, with at least some of them, part of the nature of the illness is to look at any treatment in a paranoid way. Given the nature of that illness, how do you deal with it? Are you suggesting therefore that people who, according to—and I believe as a legislator I have to go with the general consensus of the medical profession. How do you treat them?

**Dr Burstow:** First, let me say that while there are overriding opinions in the medical profession, there is not a consensus. A number of medical people have spoken out saying this is not the case. You have a consensus when there is no one who strongly objects. You have people throughout the history of psychiatry who have said this is not the case.

**Mr Sterling:** In politics we never get a consensus.

**Dr Burstow:** You said that as a legislator you have to operate in terms of general consensus. I am saying there is

no such general consensus so, no, you do not have to. People who are diagnosed schizophrenic are generally people whose trust level is low, and often there is damned good reason for their trust level to be low. I think it pathologizes the whole issue of trust by saying this is in the nature of an illness. It is not in the nature of measles, it is not in the nature of any real illness I know to be distrustful.

If people are distrustful, they may or may not have something to distrust when it comes to the treatment in question. But to begin with the presumption that there is no reason and this happens with an illness, I think, is to buy into something that leaves vulnerable people utterly unprotected.

1100

**Mr Sterling:** How do you treat them?

**Dr Burstow:** For one thing, I do not treat people; I work with people. If people work with people in ways that are trustworthy—and I have worked with many, many people who have been diagnosed by the medical establishment as schizophrenic—trust shifts; a strange thing. I do not think it would do that if it were part of a physical illness and yet it does, which suggests to me (a) that is not part of a physical illness, and (b) that it is not impossible to work with people on these issues. One has to work in a way that is respectful and that recognizes people's rights. You do that and people start to trust. I have not had a major problem of trust with people diagnosed as schizophrenic though strangely enough their psychiatrists have, their doctors have, and so forth.

**Mr Winner:** You raise a couple of interesting points I just need clarification on. You would add a couple of subparagraphs to section 56 as you have stated on page 1. You mentioned "neuroleptics or anti-depressants" and then you mention "monitoring devices or restrain the person physically or by means of drugs." Just dealing with your suggested subparagraph (e) with neuroleptics or anti-depressants, "highly damaging drugs," section 56 starts off with a little preamble which says, as you know, "unless the order expressly provides," so these things are permissible if the guardianship order expressly provides so. I assume that by adding these two subparagraphs you still acknowledge that a court may order that this kind of treatment is appropriate in an individual case.

**Dr Burstow:** I acknowledge that in fact that is the case; the court can. I certainly do not agree that a court should and I would agree that would have implications for the rest of the act. I think a court ordering any kind of treatment as medical, which has not been proven to be medical, is a problem in the first place. If you add to the fact that there is clear documentation of irreversible diseases, which these treatments cause, I think we are into a very difficult area here.

**Mr Winner:** Another thing that concerns me is that at the bottom of page 1 you describe some of your clients, women, some survivors of incest who self-mutilate and you say it would be inappropriate to confine, monitor or restrain self-mutilation.

Interjection.

**Mr Winninger:** We have had many psychiatric survivors come forward who have suggested that unless a person is a danger to himself or herself or others you should not be able to take steps to commit and restrain. Where would a health care practitioner or a guardian, for that matter, draw the line if someone is self-mutilating, because that could obviously be life-threatening?

**Dr Burstow:** I have tried to avoid a very difficult area here, and you have taken me right into it so I cannot avoid it any more. First, let me make a distinction between "self-mutilating" and "suicidal." I have worked with women who have self-mutilated for many, many years, and you would be surprised what percentage of women, because men are trying to take their hostility out on others, are trying to take it out on themselves. With all the women I have worked with, with all the people I have supervised in this area who work with self-mutilating women, the self-mutilation has never been a way of killing themselves. It has been a way of coping, a way of getting through the day, a way of numbing themselves to pain, a way of distracting themselves from child abuse memories etc. That is not what it is about, and so I think we scare ourselves when we say "This person is really going to die from this." They do not die from this so I think these things have to be separated out.

Beyond that, I have a further belief which would be very controversial and I did not want to get into it for that reason. I think there are times when people do kill themselves, and as a state we have pathologized that. We have pathologized the issue of wanting to kill themselves and yet we know that, for century after century, philosophers have put this forth as the basic human question that we all ask ourselves: Do I want to go on living or do I not? It is my strong sense that that decision has to be in the hands of the people and not of other people. When I say that, I am sure everyone's hackles go up and they say, "That's going to result in more deaths." I would like to suggest that if we did not physically stop people—that is different from offering help; I think we are definitely obliged to offer all sorts of help—from killing themselves and people did not know we were going to do that, the death rate would go down, would not go up.

I have also been specializing in the area of suicidal clients for 15 years. When people told me they were going to kill themselves, not once did I try to physically stop them, and I have not lost a single client. With psychiatrists who drug them and stop them and confine them for those reasons, I doubt whether any of them have that same record.

**Mr Winninger:** One last question, if there is time. You suggested that you approve of the amendment for access to health care records, which may be the subject of separate legislation, but you have suggested that the phrase "subject to the Mental Health Act" be deleted. There are many cases where information in medical charts, particularly in psychiatric situations, contains anecdotal or descriptive evidence of behaviour that comes from family members, friends, this sort of thing. I think one of the motivating reasons for having that caution in the Mental Health Act, so that there is a review board mechanism for

that, is danger, sometimes, to other people if all that information were disclosed. So I would ask you whether you agree that there have to be some reasonable limits on full disclosure for mental patients or possibly other patients.

**Dr Burstow:** No, I do not, so let me try to explain why I do not. I have never been locked up in a psychiatric facility, but I will tell you, if friends and relatives could say whatever they want about me and this would be written in charts and everyone in the hospital would have access to these charts and I would not know what they would say, you are damned right I would be paranoid; not because I would have a disorder, but because this is a paranoid-making situation. If there are things that people have said that for everyone's protection you do not want known, then do not have them written in the chart.

I think it is a real paranoid-making situation to have all this information in the chart with a whole bunch of people having access to it and acting in terms of it, whether it is right or wrong, because I assure you, relatives say things from their own point of view, and sometimes that point of view coincides with the patient's and sometimes it does not, and sometimes it is accurate and sometimes it is not. People need access to that kind of information. Yes, there can be times when you think it is dangerous; then do not put it in the records. Do not have everyone else being able to look at it and this vulnerable person the one person kept in the dark.

**The Chair:** Dr Burstow, on behalf of the committee, I would like to thank you for taking time out this morning and coming and giving us your presentation.

#### ONTARIO COLLEGE OF FAMILY PHYSICIANS

**The Chair:** I would like to call forward our next presenter, from the Ontario College of Family Physicians. Good morning. Just a reminder that you will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Dr Miller:** My name is George Miller. I am the president of the Ontario College of Family Physicians. I am accompanied today by Ms Terri Toffen, who is our executive officer. On behalf of the Ontario College of Family Physicians, I would like to thank the standing committee on administration of justice for allowing us time to comment on the bills relating to consent.

The Ontario College of Family Physicians is a provincial voluntary organization of family physicians dedicated to the maintenance of high standards of medical education and care in family practice. We represent educational, economic, political and social interests of family physicians as well as the interests of our patients, the health care consumers of the province. We have a provincial membership of 4,700 family physicians.

Our comments here are almost exclusively related to Bill 109. We agree with the establishment of the age of consent at 16 years. Under subsection 8(1), patients aged under 16 years are presumed incapable of consent, but if a

health care worker feels that a patient is able to understand the issues involved, the practitioner would be able to declare him or her competent and provide the service. We feel that this is appropriate, since it will give family physicians the latitude to treat minor problems in our offices while allowing hospitals the authority to develop guidelines for the provision of more complex services which would more appropriately require the consent of parents or guardians.

Family physicians frequently see children who have come to the office on their own or in the care of a babysitter or an older sibling. Most of these visits are for minor health ailments. Family physicians must have a mechanism to examine and to treat under such circumstances. This bill gives them such authority, assuming they can satisfy themselves that the child is competent to understand the nature of the illness and its proposed management. It makes sense in such situations to tie consent to the ability of young patients to understand, rather than to their age.

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However, in situations where the reason for the visit is complex or where treatment is complicated, it becomes more difficult for family physicians to satisfy themselves that the younger patient has a full understanding of the issues involved. Indeed, complex issues of medical management often tax the understanding of a mature adult. The presumption of incompetence in patients under age 16 allows physicians the latitude to ask the young patient to seek the consent of a parent or guardian if the physician does not feel that the patient has a full understanding of the proposed health care service. Family physicians would not have this option if the age of consent was lowered or if there was no age of consent.

We are glad, therefore, that the Weisstub recommendation of 14 was not followed by the drafters of this legislation. Our members believe that patients in the age group 14 to 16 have too little experience of life and are far too vulnerable to peer and other pressures to be assumed competent to consent to all health care services. Although family physicians are uncomfortable with the concept of agism, we feel that a compromise has to be made on this issue, and we feel that this bill proposes an acceptable compromise.

Subsection 10(7) creates an unintended anomaly. Under this subsection, a child of any age who refused treatment would go through the whole process of advisement, written notice of incapability and appointment of an advocate. This would obviously be inappropriate for the uncooperative four-year-old who does not want his booster shot or the six-year-old who does not want his sutures removed, both of which are very common scenarios in family medicine.

Under section 24 we are pleased to see protection from liability for physicians who treat in an emergency on the basis of a consent which they believe to be valid or who cease treatment on the basis of a refusal of consent which they feel to be valid.

We agree in principle with the concept of advance directives. However, if physicians are bound by the law to follow

these directives, it is essential that they be protected from civil suit in the performance of these legal responsibilities. It would not be fair to subject physicians to double jeopardy, where they could be sued by the patient or relatives no matter what decision was made. This immunity should also extend, however, to disciplinary actions instituted by the College of Physicians and Surgeons of Ontario. We would like to see an amendment to that effect. We note that this immunity is also extended to emergency decisions made in good faith by the substitute decision-maker, and we agree with this.

Although we agree with the general direction of the proposed legislation, we do have some concerns with the act. I would like to mention at this hearing two of our concerns. Our first concern relates to patients who harm themselves through self-destructive acts. Bill 109 gives authority to advance directives by patients, and physicians are bound by law to follow them. As we have already noted, we accept this and agree with the concept. There are some problems, however, when this is applied to self-destructive acts. Family physicians will be placed in a difficult situation if patients arrive in the emergency ward having taken an overdose of sleeping tablets and then refuse treatment. Although the patient will argue that the refusal of treatment is valid under section 23 of Bill 109, the doctor might reasonably argue that the patient's mental competence is clouded by a temporary and treatable state of depression and that the refusal of consent is not therefore valid. Since suicidal gestures are frequently the result of transient aberrations in the mental health of individuals, we feel that the law must make an exception in the case of self-destructive actions and disallow advance directives refusing lifesaving measures. A clause should be inserted into Bill 109 to this effect.

This does, of course, bring up larger societal issues, such as the competent individual's right to refuse water, food and the necessities of life for political and other reasons. Society may well believe that individuals have the right to initiate such self-destructive actions. However, the decision is of such magnitude and the consequences so final that we believe the burden in such cases should be on the individual to prove competence, preferably through a formal competency hearing, rather than for the physician to prove the opposite. This issue is, of course, extremely complex and needs much public debate. However, until it is resolved, we urge that advance directives not be binding on physicians in emergency situations when associated with self-destructive acts.

Also on the issue of advance directives, we would like to record our concerns about advance directives from minors and residents in an institution refusing consent for emergency lifesaving procedures. Members of these groups often have great difficulty establishing their rights and need the protection of society from those who might counsel them unwisely. Again, we suggest that the burden of proof be on the individual to formally establish competence rather than on the physician to prove otherwise. This could be dealt with through an amendment to the Advocacy Act, Bill 74.

Our second concern with the proposed legislation is the plight of the mentally ill, who have once again fallen through the cracks in legislation and are absent from these bills. In our brief to the Weisstub Inquiry on Mental Competency, we voiced our concern about individuals who suffer from a recognized psychiatric illness and who have no insight into their own condition ending up on the streets or in jail because the present system allows them the questionable right to remain mentally ill.

It is variously estimated that between one third and one half of the homeless in major metropolitan cities suffer from a serious untreated mental disorder. Many of these individuals, contrary to popular belief, do have homes and do have relatives who worry about them. Indeed, some of the most heart-rending submissions to the Weisstub inquiry came from relatives of individuals in this group. Yet these victims of mental illness wander the streets of our major cities, listening to the incessant siren-song of the voices in their own private world, a siren-song which dashes them on the rocks of our indifferent society.

Although treatment is available, they do not receive it because we have given the right to refuse treatment even though their mental illness by its very nature may prevent them from recognizing that they are ill. The terrible paradox in our society is that the more mentally ill you are, the less likely it is that you will receive treatment. We believe that the cause of this paradox lies in our outdated attitudes to the process of committal of patients. The system of involuntary committal, as it presently stands, is not based upon an individual's need for treatment; it is based upon a mechanism of detention aimed at incarcerating individuals who are an immediate danger to themselves or to others until the threat has passed.

Once the immediate threat of danger has passed, these individuals are free to decline treatment even though they may have a serious untreated mental illness and no recognition that they are ill. They are discharged to a community which has few resources and no authority to treat. The revolving door has just taken another turn.

Professor Weisstub himself noted that psychiatrists saw themselves increasingly as jailers rather than healers. Submission after submission to his inquiry detailed this revolving door syndrome of psychiatric institutions. It has also been commented upon by many coroners' juries investigating the street deaths of such individuals.

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There are two problems with the present, outdated concept of involuntary committal. First, the concept is global. In other words, patients effectively do not have the right to make any decisions while under such a certificate even though they may be competent in issues unrelated to their own illness. Second, it requires incarceration in an institution. This leads to the process being perceived as punitive, with all the emotional turmoil this entails, rather than being seen as a healing process.

The Ontario College of Family Physicians has gone on record as advocating a system of outpatient certification, whereby involuntary patients would be free to make all their life choices except for decisions related to their own treatment, which would be made on their behalf by substi-

tute decision-makers. This would ensure that patients who have no insight into their own illness would be able to get the care they need on the authority of their substitute decision-maker and certification would be linked once again to the need for treatment rather than the need for incarceration.

Professor Weisstub, in his report on mental competency, recognized that the issue of involuntary committal needs further study, and we would urge that this be given highest priority. The Ontario College of Family Physicians would be more than willing to work with government towards formulating a sensitive and non-punitive approach to involuntary treatment. Our present task, however, is to ensure that the legislation we are discussing today does not shut out the mentally ill. We propose that the legislation be amended to leave the door open to anticipated changes in the committal process.

In subsection 19(2) of Bill 109, a substitute decision-maker has the authority to admit a patient involuntarily to a psychiatric facility. This can only be done, however, if a court order has been obtained as described in Bill 108, section 56. Court orders are not only time-consuming and difficult to obtain, but the involvement of the court reinforces the punitive concept of committal impeding the healing process and degrading the individual. The mentally ill are not criminals.

This section should be amended to give authority to the substitute decision-maker to order treatment of an involuntary patient if the patient is under the certificate of committal. Although under our present system this will effectively mean involuntary admission to an institution, such an amendment to Bill 108, section 56, would leave the door open to anticipated changes in the committal process. This in turn would lay the groundwork for the development of a sensitive system of involuntary committal based on treatment needs instead of the need for incarceration, based on community management instead of institutional treatment and based on specific determinants of competence instead of global determinants of incompetence.

The Ontario College of Family Physicians shares the concern of many other groups, but the system of advocacy outlined under sections 10 and 11 of Bill 109 is completely unworkable. It is just not practical to withdraw authority for treatment from each and every incapable patient until he or she has been advised by an advocate. However, your committee has heard this loudly and clearly from many other groups.

Our priority today has been to focus on aspects of Bill 109 which we feel have not been adequately heard during the deliberations of your committee. The main message we would like to promote today is that the mentally ill cannot obtain the treatment they need or desire with this bill as it stands. A caring society should not abandon the mentally ill to the streets or to jails in the name of human rights. We have the opportunity in this legislation to open the door to a more appropriate and humane approach to mental illness. If the opportunity is lost, it will likely not appear again until the year 2000 or beyond.

Mr Chair, I realize it is late in the morning. I would like to compliment your committee members on their undivided

attention. I would be happy to answer any questions you may have.

**The Chair:** Thank you. Each caucus has about five minutes for questions and comments.

**Mr Poirier:** Until your presentation, I would have bet a hefty amount of money that care givers would have been unanimous in throwing out that age 16 limit for consent for children. Every group, as far as I can recall—I have been here almost 100% of the time—has come out asking to remove that age 16. You come forward and you want to keep it. This is rather interesting. I respect your position on this, but it is a heck of a surprise, because you are the first group—correct me if I am wrong—of health care givers who wants to keep it. Can you help me understand why you would have such a different position than the other health care givers?

**Dr Miller:** Are you asking me whether the age of consent should be removed altogether and any person, no matter what age, should be assumed competent?

**Mr Poirier:** I am asking you if you can help me understand why your group would have such a different position than other health care providers who would like to have it completely thrown out.

**Dr Miller:** I think a lot of the groups you have heard from so far may have been associated with institutions. In family medicine we see a lot of young patients.

**Mr Poirier:** They also claim that.

**Dr Miller:** I think if you get down into the young age group such as eight or nine years old, it is very common for these individuals to refuse treatment because they are afraid, because they do not understand what the treatment is. Under such circumstances, we have to rely on the guardians or the parents to make the decision for them. A six-year-old who refused to have his stitches out, for example, would end up going around with stitches for ever. I really cannot visualize that.

The biggest problems, of course, are in relation to birth control advice and sexual advice. Children of 14 or 15 may well have the maturity to understand all the implications of birth control, for example; children of 11 or 12 may not. If they do understand the issues involved, they may not have the emotional maturity to understand fully the decision they are making. So I think once we get down into the lower age groups, our organization is very uncomfortable with the idea of removing the age of consent completely.

**Mr Poirier:** I am quoting from the other groups of doctors, nurses and other health care givers who have come forward. They are stating: "We feel perfectly protected or very comfortable with the current protection the common law gives us pertaining to something like that. Therefore, we do not feel we need that age 16 limit." How would you respond to that? I am trying to understand the black-and-white difference.

**Dr Miller:** At the moment, as far as I know, doctors really do not have any authority to treat under these circumstances, as I understand it. I do not understand common law too well but, as I understand it, there is nothing that actually gives us the authority or the right to treat

people under 15 at the moment. I have no objection to a law that gives us authority to treat. I have problems with a law that takes away authority to treat.

**Mr Poirier:** I can understand that.

**Dr Miller:** Subsection 10(7), for example, takes away our authority to treat a child who refuses treatment even though he or she is under age. This is where I have the difficulty.

**Mr J. Wilson:** Thank you very much for your presentation. I think this is an important point as we wind up the hearings. Perhaps we could ask either the parliamentary assistant or counsel to clarify, in 30 words or less, the common-law standard right now with respect to treatment of children.

**Mr Wessinger:** The common-law situation is that the matter of capacity is not a question of age; it is a question of determining whether the child has the capacity to understand the consequences of the treatment. If the child has that understanding, then of course he would have the capacity to consent to the treatment. As a result, a child could be competent at age 12, or with respect to some treatment, such as the thing of stitching up a wound, maybe a nine-year-old might have capacity in those types of circumstances. On the other hand, you could have a situation where a 16- or 17-year-old might not understand a treatment decision, in which case a medical practitioner would determine that, if the person did not have capacity. So it is very flexible at the present time.

That is the way the common law is. There has been an amendment put forward by the Conservative Party with respect to deleting the reference to age, which would put it back to the common-law position.

I can understand your concern about subsection 10(7). Certainly it is not the intention that this would create a problem, and we are looking at clearing up that ambiguity.

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**Mr J. Wilson:** Thank you, Mr Wessinger. You have explained fully the intent of our amendment.

I do have a question, though, that pertains to page 9 of your brief. For instance, Dr Bonnie Burstow appeared just before you. Not to put words in her mouth, but presentations like hers or similar to hers have told the committee that unless there is a clear sign of physical illness—for instance, she indicated she did not consider schizophrenia to have any physical signs, and therefore it was not an illness; that many types of mental illness are really subjective matters when it comes to diagnosing those and they are really in the eyes of how others view the so-called mentally ill person. I think it ties in with your outpatient certification proposal here. Have you had an opportunity to discuss this with a number of mental health organizations and, if so, what has their response been to this idea?

**Dr Miller:** The outpatient certification process first came up through coroners' inquest reports. It appeared in the recommendations of several coroners' juries. We took it up from there, and we have discussed this internally with our own organization. I do not have the response so far, say from the schizophrenic organizations. We have put this

idea out to the Metropolitan Toronto Health Care Coalition. We do not have a response back yet from them.

**Mr J. Wilson:** I get the feeling the government itself tends to listen a great deal to groups that say: "Well, these things are subjective really. These people are not mentally ill, it is just the way you view them." I would think groups that are of that opinion would resent that a substitute decision-maker can make all choices except those choices pertaining to their treatment. I get the feeling from weeks of hearings now that a lot of people perceive there should not be any treatment, just counselling and good neighbourly relations for these people.

**Dr Miller:** There is a great deal of denial about mental illness in the community. A lot of this denial is from patients who have been through the process of being mentally ill. We are not suggesting that doctors make these decisions, but we do feel that under certain conditions where patients have no insight into their own illness—and there are definite medical illnesses that have these characteristics—these cannot be treated by psychotherapy. Attempts to treat schizophrenia by psychotherapy have been going on since the 1930s and 1940s and have been totally unsuccessful. Schizophrenics can be managed by agreeing with their delusions but schizophrenics cannot be cured by psychotherapy, as far as the medical information I have seen is concerned. What we are advocating is that because these patients with serious mental illness are not able to make these decisions themselves, that decisions be made by a substitute decision-maker.

There are many occasions where a doctor's advice is not taken. We expect there would be many times when we would explain the pros and cons of treatment to a substitute decision-maker and the substitute decision-maker may decide not to take our advice. But at least if that happens, someone is taking responsibility for that mentally ill patient. At the moment, once the mentally ill patient refuses treatment and leaves the doors of the hospital, absolutely no one has taken responsibility for that decision. That is why they fall through the cracks.

**Mr J. Wilson:** That is a very good point. Thank you.

**Mr Wessinger:** With respect to your brief, I would just like to make the comment that I can certainly understand the health practitioner having a protective attitude with respect to patients, but this legislation really also has to balance that with respect to the question of patients' rights. Certainly we have had a lot of evidence of misdiagnosis with respect to the area of psychiatry and treatment being given which has had very bad effects on psychiatric patients. I think maybe that has to be taken into account in this whole question of how we deal with consent to treatment.

The other point I would like to make is the matter with respect to commitment. This legislation does not deal with the commitment process; that is under the Mental Health Act. We are really dealing with consent to treatment. The effect of this legislation would be that even when a person is involuntarily committed, that would not take away from him the assessment of the question whether he had the capacity to consent to a particular treatment in spite of the fact that he was involuntarily committed.

**Dr Miller:** I think the door still has to be left open for changes in the committal process. At the moment the committal process is just one of incarceration. The law does not recognize the need for treatment in the committal process at all. It only recognizes the need for incarceration. As such, it is a terribly punitive attitude towards involuntary treatment. There are people who do not accept that the involuntary treatment is necessary under some circumstances. There are some people who deny mental illness completely and say it does not exist. But if you accept that under certain circumstances involuntary treatment is necessary, we have to work out a humane and non-punitive way to do that. Although I agree the legislation does not deal directly with the process of committal, it could leave the door open to changes in committal if we allow it to do that.

**Mr Wessinger:** The only comment I would like to make is in fact that this legislation does provide for involuntary treatment in the case where a person is determined to be incapable.

**Dr Miller:** From a court order, yes, which increases the punitive aspect—

**Mr Wessinger:** Not only from a court order. Once the person is determined to be incapable, then of course the substitute decision-maker can make that decision.

**Dr Miller:** If the patient agrees.

**The Chair:** On behalf of this committee I would like to thank you for taking the time out this morning to come and give us your presentation.

I have one announcement on scheduling for the committee. We will be doing the teleconferencing in room 151 promptly at 1:30. We ask that everybody be there strictly on time, because we have to be out by 2.

**Mrs Sullivan:** Mr Chairman, I want to indicate that I have a motion to present to the committee at whatever time the Chairman wishes to deal with it.

**The Chair:** Thank you.

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HUGH TAPPING

**The Chair:** I would like to call forward our next presenter, Hugh Tapping. Good morning. Just a reminder that you will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Mr Tapping:** My name is Hugh Tapping. Almost 30 years ago I was involved in an industrial accident. Unfortunately, it was the mental health care industry. Like most industrial accidents, quite a few different things had to go the wrong way in just the right sequence of events. Unlike most industries, quality assurance and quality control are not something this field has paid very much attention to. Everyone seems to have very strongly held opinions, I am no exception to that.

I do not have a presentation in a brief for you today. I was writing for hours last night after I heard that I would

be speaking today. After watching the news I took a look at what I had written and had to start all over again, so I doubt I shall be able to read my notes. I am not going to give a full brief. One of the reasons is that it is the last day. I suspect by now most of you have had enough.

You are legislators. You make the laws. I am not going to take you through all this clause by clause. I am neither a lawyer nor a legislator. However, now that it is your last day and you are going off to do the work behind closed doors, I do want to try and remind you that legislation does not equal social change. Legislation can help and legislation can hinder. As lawmakers you folks are stuck in the position of the carpenter who only has a hammer. No matter what the screw in his tool-box is, there is only one thing he can do with it. You really should use a screwdriver on screws, folks. That was an attempted joke.

I have sat through quite a few of the briefs and deputations to you. You have sat through all of them. Congratulations. Some two years ago now the federal government released a discussion paper for federal-provincial consultation called *Striking a New Balance: A Blueprint for the Regulation of Ontario's Health Professions*. That is what you people must do. You have heard much about a very polarized scene. Many people come here and give you a very black-and-white picture. Part of that, I think, is due to the very way the consultation with the public happens. Most of us do not do this sort of thing very much. This is kind of intimidating. You are used to it, but believe me, you are only used to sitting there. This hot seat where I am is different for everyone.

You must strike a balance according to what you have been told. I beg you please not to continue to just do party politics with this. Please remember this whole advocacy business got started with Father Sean O'Sullivan. He was as rock-ribbed a Diefenbaker Tory as you will ever find and the youngest member ever elected in Ottawa. It was the Liberals who appointed Father O'Sullivan and now it is the New Democrats who have inherited carrying on the work. I am concerned about some of the almost autopilot, automatic responses I have heard in the questioning in this committee. It is time to get over that, folks.

I would like to give a bit of a history lesson before we get into the questions and answers, because things are getting better. They do not get better because of legislation. Sometimes they seem to me to get better in spite of legislation.

This whole advocacy proposal is not just about the law; it is about social change. I do not really know how much influence a legislature can have on that. I think most people recognize that it reflects rather than leads society's values.

I have several books here. You have heard about this one: *Madness in the Streets*. You have been told to read it by at least two presenters. I agree that you should read this thing. I disagree completely with what is in this book. I thought they had me labelled as being paranoid. This is truly amazing stuff. It explains how the homelessness situation is the product of a new left conspiracy to make our cities ungovernable so that the revolution will happen. It posits that some half a dozen perhaps justifiably angry

ex-psychiatric patients met a bunch of law students with an interest in civil rights and a habit of taking LSD on their weekends and have entered into a conspiracy which has given us the situation we have now. That is one explanation for it. I am a science fiction fan. I urge you to read this one because it is an alternative reality story that does include quite a few references to Ontario.

My marker is at electroshock. According to this footnote, this Legislature went even beyond the review committee's recommendations. These are the review committee's recommendations. Similar to advocacy, it was Keith Norton who began this and it was Murray Elston who received it.

The vast majority of these recommendations have not been implemented, which leads me to another interesting and important point: You will never get it right. Do not wait and discuss and debate and try to get this written so that everybody will be equally unhappy or whatever. It will never be right. Just get on with the work.

I have here a press release from Mr Elston's office that says things had been done to implement this report, but they have not yet been done—such basic things as a written piece of paper with information on it for patients, their families, their substitute decision-makers, whatever, which Mr Elston said were done in 1986. It is still in the process of being written. Do not make that mistake with this proposed bunch of legislation. It has been studied to death for many years but it is people like me who would end up dying.

Things are getting better. This book is about 10 years old and is a product of OPSEU, the people who work in our institutions. There are two bits from it you must know about. They ask the question, "Who should be called to account for the humiliation and distress endemic in a system that often seems to be as psychopathic as any of those who need it?" Things are getting better. OPSEU no longer talks about psychopaths and so on.

You heard yesterday from Professor Lightman. Here we touch on the boarding home situation as of 10 years ago. Too often there are no standards. The potential for something better is there. A few are improvements on the institutions and they show up in their residents.

One such operation is a 25-resident boarding home on about an acre of land just outside Orillia. She is the kind of operator who is firm enough to say to a newly arrived ex-patient threatening her with a small table he had picked up in the kitchen, "You do that and I'll hit you with this," and she picks up another table. Nowadays that is generally recognized as inappropriate for a staff member, when someone is threatening violence, to pick up a table and threaten back. Ten years ago this was being portrayed as one of those better places. That place was called Cedar Glen, folks, and the operator at the time is named in here.

1150

This is not a product of anti-psychiatry or anti-medicine; this is the product of the Royal College of Physicians and Surgeons of Ontario. Alberta yesterday released a similar report. All our institutional care systems—it is not just the psychiatric field—need to have a serious look taken at them.

When we were in the near-permanent Progressive Conservative government era, both opposition parties wanted to see a royal commission of inquiry. Both of the parties that were then in opposition have had a crack at government. It is not just psychiatry, it is not just institutions for the the mentally retarded, it is not just for the children's or native Indians' schools and so on; it is all of them. We have to live with that history. I still would like to see a royal commission of inquiry, simply so that we could all know what that history is.

I have page after page of notes about specific things I have heard which I would like to refute. I am not going to do that. I will try to find one other sheet. One of the things that does concern me, whether I agree or disagree with what people are saying, is the way people say it as if it was the truth rather than their opinion.

Now, I understand that I have not been sworn in here or anything, and it is just as well. The number of charges which would have to be laid in what I have heard from some people here, on both sides of the question, incidentally, is really of concern. For instance, there is a coalition of organizations which has been very eloquent in its opposition to this. That is their opinion, that is fine, but yet they insist—I have checked the Hansard; I have looked at the pinks, as I heard it, as it is written—that they are the ones speaking for the professionals and the families and all the care givers involved. It is not the case; it is half a dozen organizations.

The Ontario Advocacy Coalition, which you heard from, has 35 organizations in it. The Association for Community Living is almost exclusively family members. People First is exclusively people with a "retarded" label. This pro-advocacy coalition, by the way, has everything from the association of Jewish seniors to AIDS Action Now to the Six Nations to a bunch of groups that, in all my years, I have never heard of. It concerns me that it has been presented to this committee that there is one organization, one coalition with one piece of the truth. That is just not the case.

How are we doing for time?

**The Chair:** You have just over 15 minutes left.

**Mr Tapping:** Okay, this will do to stimulate some questions, I hope. I am looking at an article from *Psychiatric News* of a year ago by Dr Theodore Lidz, sterling professor of psychiatry emeritus at Yale University school of medicine, career investigator at the National Institute of Mental Health, 1961 to 1978. He is not some ranting collant psychiatrist. This story is *Optimism in Treatment of Schizophrenia is Still Premature, Says Expert*.

You have heard testimony about how it is known to be a genetic disorder. Dr Lidz points out that there may well be a predisposition and so on, but the concordance rates among identical twins for tuberculosis and polio were about the same as what is now being found for schizophrenia. These patients may, for example, be at the end of the distribution curve of neuromechanisms, rather than possess an abnormal gene. He goes on to point out that all the proofs from the CAT and magnetic resonance and the gene

scannings are controversial, simply because most people are labelled or controlled within normal limits.

The one finding in research, according to Dr Lidz—it has been replicated or found independently by experienced therapists and investigators at Yale, NIMH, Palo Alto, France, Japan, Finland, Tunis and elsewhere—is that these patients have been raised in fairly specific types of seriously disturbed or distorted families.

I do not agree with all I am reading to you here, but I want to point out that there have been medical doctors coming to you and saying things that were their own opinions and prefacing them by saying things like "established," "scientifically proven," "documented," and so on. It is just not the case. Your job is to take everything you have heard with a large grain of salt and do the best you can.

I do not want to see this delayed much longer. This whole advocacy thing came up long before Father O'Sullivan was appointed to it. My personal experience in the field goes back to the 1960s. It has been about 10 or 12 years in this province that we have been talking about doing something like this, and let's get on with it, please. If you study it until you know it all, it just will not happen.

Questions?

**Mrs Sullivan:** I think that for all of us, Mr Tapping has spoken about the necessity of reaching a balance in terms of dealing with this legislation, and my only comment would be that it is our hope that we will be able to do that.

**Mr Malkowski:** I think it is important that we hear what you have to say, and it sounds like you are supportive of the concept of advocacy. We would agree 100% that it is time for us to take action and to set up an advocacy system at this time.

**Mr Tapping:** Please, just set it up. I love the way this advocacy commission proposal—I can quite agree with some of the members here that it is really strange the way it is being set up, but new things always seem very strange. This is almost a self-help thing. The advocacy commissioners are not going to be looking for yet another bureaucracy. Those commissioners will have lived their lives in and among bureaucracies, and they are not going to want to do that. They will want to see advocacy happening.

There are obvious concerns in the legislation about things like confidentiality, but when you have lived in a situation without confidentiality of any sort, including the right to wear clothes, you will be really concerned about other people's confidentiality. You will not need everything written down to tell you what to do; you will be able to work from your own experience. They will be able to, but please, leave it up to the advocacy commission. Whatever amendments and so on you want, let them be done with dispatch. Let's get on with it.

**The Chair:** Mr Tapping, on behalf of this committee, I would like to thank you for taking the time out this morning and coming and giving us your presentation.

Just a reminder that there will be a subcommittee meeting immediately. This committee stands recessed until 1:30 this afternoon.

The committee recessed at 1200.

## AFTERNOON SITTING

The committee resumed at 1335 in room 151.

ELDON HARDY

**The Chair:** I would like to call this committee back to order. Our next presenter will be Mr Eldon Hardy. We are discussing Bill 7, the Powers of Attorney Amendment Act; Bill 8, the Natural Death Act; Bill 74, the Advocacy Act; Bill 108, the Substitute Decisions Act; Bill 109, the Consent to Treatment Act; Bill 110, the Consent and Capacity Statute Law Amendment Act.

For your information, the committee members who are present are the Chair, Mike Cooper, Mrs Sullivan, Mr Poirier, Mr Chiarelli, Mrs Carter, Mr Wessinger, Mr Winninger, Mr Morrow and Mr Malkowski. Are you on line, Mr Hardy?

**Mr Hardy:** Yes, I am.

**The Chair:** You will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. Could you please identify yourself for the record and then proceed.

**Mr Hardy:** My name is Eldon Hardy. Right now I am calling you from the medium security unit at the Kingston Psychiatric Hospital. Because I am presenting at all today, in the manner in which I am, I think I want to address that first. It might be the only issue I address here and it is specific to Bill 74 and to advocacy for the vulnerable in Ontario. I am going to begin by reading a letter which was faxed to the committee from myself March 9. It is addressed to Mr Cooper.

"Dear Mr Cooper:

"As I understand it, your committee will have been requested to seek a subpoena under the Speaker issuing a Speaker's warrant to ensure I am allowed to travel to Toronto and make my presentation concerning Bill 74. I urge both you and your committee to pursue this unusual step to both maintain the integrity of these hearings themselves and prevent my once again being silenced while attempting to identify serious problems within our system of justice as it pertains to providing advocacy to the vulnerable.

"It is my respectful submission this committee should not allow those who would necessarily not be favoured by a strong advocacy system from continuing to prevent my personal appearance at Queen's Park. The committee's entertaining any suggestions to travel into Kingston, if such has ever been being seriously considered, would itself leave a perception that the voice and rights of the vulnerable will continue to be compromised even after Bill 74 is in place. Anything short of my personal appearance at Queen's Park, as per my original letter of confirmation dated January 24, 1992, would certainly leave me unable to accept we are doing anything more than giving lip service to advocacy again in Ontario for the second time this decade.

"Thank you for any efforts you and your committee members would undertake in the above regard."

Your committee, Mr Cooper, followed up from that with this letter faxed to the administration, the people holding me. Your letter was dated March 12 and they received it March 12. It reads:

"Mr Eldon Hardy, who is currently residing in your facility, has requested to appear before the standing committee on administration of justice, to comment on one or more of the abovenoted acts." Those would be the acts you referred to at the outset here.

"The committee has instructed me to relay to you our strong desire that this individual be allowed to appear before the committee. Mr Hardy would be scheduled to appear before the committee on either 24 or 25 March, 1992. The hearings are being held in committee room No 1, in the Legislative Building."

For your information, I find that this is a very poor arrangement we have come to and I consider it is going to always be the issue. It certainly has been in the past for me and many others I know of, certainly in the facilities like I am in, where we for ever compromise the voice of the vulnerable. I have in particular experienced this with psychiatric patients. In every effort I have made over many years in one way or another, no matter what effort it was or how great the effort, those who would necessarily be the ones we need strong advocacy to go up against always succeed in compromising the voice of the individual.

The fact that I am sitting here in a common area in the medium security unit, not even at a phone which as I was originally told would be at least in a private office to give me some space, tells me that we are not really prepared to provide strong advocacy; at least I have to look at it that way. I am very concerned that I am sitting at this phone rather than appearing before you and that those to whom we need to address this simply seem to walk all over us.

I want to read to you part of the response, dated March 6, that Mr Larry Taman, a lawyer who tried to negotiate for several weeks to get me before your committee, sent to the administrator, Mr Wayne Barnette. This was in an attempt, probably for the third time, to get cooperation to allow me to present before you people. I will begin his letter:

"For reasons which I think will be apparent upon reading this, I write to you instead of to Dr Jones in a last effort to obtain your hospital's agreement to take Mr Hardy to give testimony before the justice committee of the Legislature.

"In Dr Jones's communication with Mr Hardy and in Dr Jones's communication with me, he said that Mr Hardy would not be transported to the hearing because the hospital cannot afford to do so. I attach his memorandum to Mr Hardy of February 18, 1992. You will note that there is nothing in this letter to suggest that there is any other reason.

"In my subsequent conversation with Dr Jones, he indicated that he did not agree with my assessment that it was in Mr Hardy's interest to be given the opportunity to participate in this way. None the less, this was at no point advanced as a primary concern. Now the legislative committee

has offered to pay all the costs for Mr Hardy's attendance before it. I understand that Dr Jones is still unwilling to permit him to attend. He indicates that it is true that the committee does have a teleconference facility which could be made available for the purpose of Mr Hardy's submissions.

"I am at a loss to understand why the hospital will not transport Mr Hardy now that the standing committee has agreed to bear the costs. For Dr Jones to determine that teleconferencing is an adequate substitute is merely to substitute his judgement for Mr Hardy's, in a manner in which Dr Jones has no mandate to decide for Mr Hardy. I believe that Mr Hardy will see this as a real breach of faith.

"For my part, I spent a good deal of energy in attempting to arrange for Mr Hardy to attend. I am left wondering whether these efforts have been met with a proper response on the part of the hospital. I would again reiterate my request that you intervene directly to permit Mr Hardy to attend in Toronto"—that was for an earlier date of Monday—"I would say to you respectfully that the institution has not advanced any interest other than a resource interest in declining to do so. Now that that obstacle has been overcome, I do not understand what proper reason can be advanced for failing to accommodate Mr Hardy's request."

I think those three letters that I have read sum up very adequately the very point. Here is a lawyer of some standing who had worked very hard with this issue, negotiating with these people to allow me to present directly before you. There was no reason I should not have been able to. In fact, any reason they had was removed.

At one point, the doctor indicated—and I will read part of his letter—"This is atypical." In one part he says that he and a Dr Chan "are of the view that your appearance before the committee"—that is my own—"would be countertherapeutic and that this negative effect could be tempered by a proposal for a conference call, which would be somewhat less so."

Every excuse is advanced to prevent either myself or others from being able to present wherever it might have some significant impact. I do not know where you think this could go today, beyond my making this particular point. I think it is one you are going to have to look at time and time again, and certainly the Advocacy Act, Bill 74, is going to have to have some teeth in it.

I can only go back to the psychiatric patient advocate office in the early 1980s. There were many of us then, and I was one of them, who had great concerns about how that office would operate and what sort of strength it would have. As it turned out, it had very little. I was interviewed by *The Star*, I believe in 1983, and they quoted me then as stating, "All should not be considered well in the mental health system simply because the patient advocate office is on the job." Ten or more years later, that is exactly the case here. We have a bureaucracy inside a bureaucracy, and the patients are kept swimming in that.

We envisioned then that we would not have strong advocacy. We are looking at Bill 74 and I can tell you that my brief, which I did prepare and hoped to present to you in person today, is entitled *Advocacy For and By Ourselves*, because basically I think that is where it is at. Psychiatric patients or vulnerable persons, all those who are capable,

are going to have to be allowed to advocate and with laws to back us up. When we have to rely on others who have not had our personal experiences, we do not have any opportunity whatsoever to make any impact where it is going to matter.

Many of us can advocate but we are not allowed to. When I speak up in these institutions they shut me up or they compromise my voice. Because I dare to take up the issues with these people, I wear the worst psychiatric diagnosis and prognosis. Everything is done to sit on me. You saw a very good example of that in that every effort made to get me before you has been stopped simply by people putting out such opinions as, "It would not be therapeutic." I do not know what could be more therapeutic than my having an opportunity to address some of these issues, but I was left this morning, at the last minute, being informed that I am going to have to settle for talking to you on a phone. That seriously compromises everything I have ever been trying to do, and it certainly does not give anyone a very good impression about where Bill 74 will go.

The psychiatric patient advocate office had no teeth. It should have had sabre-toothed fangs. You need trouble-shooters in these systems and people you will thoroughly back up. I do not see too much of that yet in Bill 74, but you must realize that my communication with you earlier—and I am not pulling punches on this. You have compromised my voice. You have allowed it to happen. You did what you could in your letter requesting it, but they were able to simply ignore you. They were able to simply ignore a lawyer, and they have ignored me easily.

I do not know where you want to take this one here. I do not have a lot more to say because I am quite angry about this. Does anyone there want to address this one?

**The Chair:** As you began your presentation, Mr Wilson and Mr Mancini joined the committee, just for your information. There is about five minutes for each caucus for questions and comments. I remind members to raise their hand before they speak to make sure the microphone is on or he will not be able to hear you.

**Mr Poirier:** Jean Poirier here, Mr Hardy. I realize you could spend many hours to make the point about the nature of your presentation today, but did you not want to elaborate on the particular points you would have wanted to make today, regardless of how you are making them? We are here. We are listening to you. I for one would like to hear your comments about Bill 74 and any companion legislation. Do you want to do that?

**Mr Hardy:** I can read part of my brief. I guess I take the position that it is an issue primarily of credibility. I do not see much credibility in what we have done for vulnerable persons over many years. When we talk about empowering psychiatric patients or the vulnerable, we do not talk very much at all about depowering the powerful, those persons who have all the power over us. They seem to get more power as we go.

**Mr Poirier:** You seem to have studied—

**Mr Hardy:** I am trying to get to a particular recommendation here. I addressed an issue with a couple of

insurance companies and consultants with the Workers' Compensation Board, who as you may know in the last four or five years have been looking at the issue of chronic stress and whether it should be compensable and how they would go about it. In my conversation with them, they wanted me to send my recommendation to them. I suppose one could consider it a somewhat radical view, but they are very much interested in it. I wonder if I could read that to you.

**Mr Poirier:** If you feel it is part of what relates to Bill 74, go right ahead.

**Mr Hardy:** Yes, it is. Persons employed within the mental health system, particularly front-line workers, should be required to undergo full independent assessments by either psychiatric or non-psychiatric specialists to have determinations made as to their mental fitness to continue in their current employment. This recommendation is specifically warranted in light of the Workers' Compensation Board considering a policy proposal on compensation for disablements arising from workplace stresses. This group of workers often find themselves laying claim to their workplace being an unusually stressful workplace. Often expressed by these workers is that their particular workplace consists of working with persons who are often portrayed, unfairly and inaccurately at times, as difficult persons to work with.

This itself can easily come to be considered as the basis for confirming that they work in the unusually stressful environment to give anyone associated with WCB policy proposals some considerable cause for concern.

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The many workers in the mental health system who may be potential claims present not only the possibility of staggering costs but many other costs which are not as easily recognized. Psychiatric patient advocates have operated in the system since 1983 and too often mental health workers were able to use the advocates investigating a complaint as grounds for making the argument that the workplace has now become too stressful. This acts to intimidate and see less serious pursuit of the vulnerable person's complaint of rights being violated and increases the chance of the guilty worker being either absolved and the abuse continuing unchecked or a watered-down conclusion drawn from any investigation, which has the same end result.

It is my position that the coming into effect of an Advocacy Act should not be associated with seeing the vulnerable in these workplaces becoming scapegoats to allow claims receiving virtual rubber-stamping simply because workers are unable to cope under stresses however unique the stresses may be in their particular job.

The employer has a right to know, and I believe the legal right to require the employee to show through testing, that the worker is psychologically fit to meet the demands of the job while not compromising on the quality of service for which they were hired, whether this has been a requirement of their employer at the outset or not. The employer has had the legal right, for example, to require his employees to minimally obtain registered nursing as-

sistant certificates, while evidence of mental fitness may not have been a requirement when first taking employment. In a mental health facility, it nevertheless has been essential to upgrade the care in the facilities to the new standards needed to meet in order to earn hospital accreditation.

Just as has been the case before now, it again calls upon the employer to upgrade his or her skills or other job-related qualifications specific to a particular type of work and to demonstrate possessing these qualifications. Just as important, it is the right of the vulnerable to also know that persons caring for them are qualified and are not going to act to sabotage programs designed for the protection of the vulnerable.

Certainly the resistance from unionized employees has been considerable in institutions in the past when the rights of the vulnerable were seen as threatening to the worker and this has led to the workplace becoming more stressful as a result. It is always within the administrative mandate to either improve or ensure the quality of services being provided to the vulnerable inside the particular facility.

I believe further that a new advocacy program will act as a catalyst for a more aggressive renewal of the principle protecting the rights of the vulnerable and to ensure they are not in the environment which is oppressing or abusing them. This is sure to bring renewed calls from mental health workers and their unions on the new stress levels they are experiencing, how it is all interfering with treatment, or aggressive campaigns complaining that security and good order are threatened etc, all of which will be designed to neutralize the effectiveness of the advocates.

This occurred when the Ontario psychiatric patient advocate office began its efforts to protect the rights of psychiatric patients. It is therefore doubly important that the relevancy between compensation for work-related chronic stress and the purpose of Bill 74 not go unnoticed. The mental health worker should have to show that he or she is capable of having the motivation to develop the appropriate attitude and willingness to participate without succumbing to stresses, real or imagined.

I am deeply concerned about the consequences for the vulnerable in institutions where the employer may entertain many oppressive—oriented towards the psychiatric patients—measures to satisfy front-line workers of a near stress-free workplace or run the risk of seeing a large increase in stress claims with the associated financial cost.

The employer may become pressured to escape these costs while the employee may directly or indirectly, for self-serving interests, act to see that these particular workplaces remain seen as highly stressful environments to facilitate the easier validation of a claim to the WCB adjudication process.

At issue is how much more difficult it will become for the vulnerable in these institutions to have their complaints of abuse addressed inside a framework which is likely to become more and more oppressive, due to the competing interests of labour and employers seeking to have the working environment either more or less stressful.

Many staff complain of being under stress the instant a complaint of abuse is made against them. Often the more

serious the complaint of abuse, the louder the claim of stress is made. This could too easily be used as a ploy to detract from the main issue of the complaint and prematurely be acting as an indication of innocence on the part of the worker. Administrative and management levels will become more inclined to want to discourage the patient from registering a complaint.

I would like to see this recommendation serve to bring the issue of mental health workers being fully tested and assessed taken up with the appropriate ministry levels with a view towards policy development for workers within Ontario mental health centres, hopefully to coincide with Bill 74 becoming legislation.

I do not know what you make of that one, but I have talked with an awful lot of people and they agree with me that we have an awful lot of people who work in the system who actually create more problems than one could ever solve with any advocacy program. Often, and I have experienced it in the last two years directly, where every time an issue is brought up—the advocates at some times have brought things up and they were challenged by unions, basically to intimidate them, hollering that they were creating too stressful an environment. Every time a complaint is brought against one of them, they are under stress; everybody backs off.

I think, myself, this is perfect timing. Those I have talked to feel this is something that should be seriously looked at. Apparently, with all those who submitted on this particular proposed policy, the unions and whatnot, all of them, not one of them wants to be seen by a psychiatrist. They all want to be seen by non-specialists. They all have good reasoning, it would appear, but they certainly want to be covered for it. We have experienced it. There was a disaster down in California with this one, I think.

In any event, I present that view to you on this sort of thing, and you might want to look at whether this should be considered in any way because I see some relevancy here. Usually the workers who want to be off the job all the time create the most problems. That is usually an escape hatch.

**The Chair:** Thank you, Mr Hardy.

**Mr Hardy:** I know the kind of problems this creates in a facility when you have—

**The Chair:** We have to move along.

**Mr J. Wilson:** Thank you, Mr Hardy. I think your brief sounds quite comprehensive and I hope we get an opportunity to read it.

I want to make a brief comment. You mentioned in your remarks that the government had done all it could to ensure that you could appear here today. You are aware that a warrant could have been issued and the Legislature reconvened. Instead, the government took the route to send a couple of what they must have known to be useless letters to the administration of your facility. We argued that the letters would not do anything and knew you would not be able to appear here as a result of those letters. I want to make sure it is on the record that that is an option open to the government, Mr Hardy.

**Mr Hardy:** First of all, I understand that the committee did all it could. I have no quarrel with that. My issue was that despite their many efforts, all it took was for those persons who, as I said in my letter, would necessarily not be favoured by a strong Advocacy Act, to say no to all of you and you could not do anything about that.

How could you possibly see yourselves—any government, whether the NDP government or some other government—backing up an Advocacy Act, how could you see that happening if every time, no matter what your efforts were, all those other persons need to do is dismiss you? That is basically what happened here. What teeth would there be in an Advocacy Act?

**Mr J. Wilson:** That is not exactly the way it is. The point is that there is an avenue that was not exercised, and I am not going to comment on whether I would have agreed with that avenue, but it is one the government did not exercise, so to be totally critical of the administration is only placing part of the blame where it should be.

**Mr Hardy:** Where do you think the rest of the blame is?

**The Chair:** Thank you, Mr Wilson. Ms Carter.

**Ms Carter:** Thank you. This is Jenny Carter speaking. I want to assure you, Mr Hardy, that we did everything we could to get you here. I should point out that if we had gone for a special warrant it could not have taken effect until after the House had resumed sitting, and this is the last day of hearings.

We certainly hope with Bill 74 to reach all vulnerable people, and you have said it needs sabre teeth. I wonder if you have any suggestions as to what amendments could be made to that bill to give it the sabre teeth you are suggesting.

**Mr Hardy:** I am concerned about rules of evidence. I believe stricter laws are required to protect the evidence given by vulnerable persons in complaints of abuse from being unjustly and unreasonably stamped with psychiatric opinions etc, which have the effect of confusing the issue of fact or operate by design to distort the seriousness of the abuse complained of. Recent changes in legislation affecting warrants of the Lieutenant Governor are limited when issues of a person's mental health may be presented before the facts of an alleged offence are examined or established. The rationale for such legislation supports the need for protection when vulnerable persons act as witnesses and give evidence in cases of registering a complaint about abuse.

That is in part 1 recommendation. I do not complete it here; I have taken a lot of time already.

The fact of the matter is that for something to have any teeth, I do not know how it is that we can have hundreds of psychiatric patients—this has happened time and time again—line up one after another and all repeat virtually the same thing about a particular abuse and everybody just sits there and listens to it and it just goes by the wayside. Two people can show up for work in the very system they are complaining about and say the complete opposite, completely deny it and suddenly the evidence of those persons means nothing. I think there is something wrong when we cannot have rules of evidence that prevent having the evidence of

people who are vulnerable, and certainly psychiatric patients, just being simply dismissed out of hand, because persons who would necessarily be being complained of can just have it dismissed on the basis of presenting psychiatric evidence.

It goes on all the time. The first time there is a serious complaint of abuse there is a hearing, whether it is a formal hearing in court or a health discipline board or an inquiry or inquest. A fight begins about producing confidential information about the patient, which is designed to present those very psychiatric views to undermine what the patient or the vulnerable person is saying and have it dismissed out of hand or prejudiced.

I would like to see rules of evidence come into place. I think the government needs to look at limiting when this kind of thing can happen. Also, it is often fought over for weeks and months at a time, about producing confidentiality into an issue, and that sometimes is a stalling tactic used very well by the person you might be complaining about, delaying tactics. They fight over whether it can get introduced in the first place. It usually ends up with its being introduced, so by the time the vulnerable person shows up with the evidence, rather than the evidence being heard on the merit of what is being examined at the time, it is dismissed.

I would like to see stronger rules of evidence, stricter rules of evidence drafted to prevent this sort of thing. That would give it more teeth so that at least when a person is complaining or has something to say, it is not being dismissed out of hand and has the same weight or at least significantly the same weight as it would be if another person without a disability was presenting it. We do not have that protection anywhere in law. I think you are going to need laws like that. I do not think you should be waiting to think of things like this after the fact either.

There is another recommendation I think was completely overlooked in Bill 74—perhaps not completely. It concerns what I would propose for a revision. I will read that; it is short. "The proposed Advocacy Act leaves it to be understood that minority groups will receive every effort to 'ensure equitable representation on the commission.'" I question strongly whether it is advisable to leave one particular minority group of vulnerable persons to have every effort made after the fact of legislating Bill 74 when they could and should be written clearly into the act now.

The act should have written into it now to include on the commission persons whose sexual orientation has resulted in their being victimized daily in our institutions and by society generally. Persons who are gay, lesbian, bisexual, transvestite or transsexual are wide open for abuse even without being under any disability. Those who come into our penal institutions or into the psychiatric professionals' domain of the mental health system are severely ostracized by the psychiatric profession and other health care workers from those within their own peer group inside the institution.

This particular minority group's vulnerability could not be addressed any more adequately than it has through an 8-page submission dated March 6, 1992, which is submitted in writing via mail to this committee from Mr Richard Elliott on behalf of the Lesbian and Gay Association of

Kingston. As a member also of the Queen's University student community service group, Mr Elliott presents more than sufficient reason for seeing that this group of vulnerable persons does not need to fight to find themselves recognized as persons in need of advocacy.

What is clearly being said there is that it should be written into the act that they will be represented and not simply left in "minority groups" and they will have to fight later. That particular group of people has to fight all the time to get any kind of recognition. Certainly they are going to need advocacy.

**The Chair:** Mr Hardy, on behalf of this committee, I would like to thank you for your presentation today, although under somewhat awkward circumstances. Could you please stay on the line for a few moments after we are done here?

**Mr Hardy:** I did not want to give the impression I was attacking the committee in any way when I made my point about not being able to get there today. I want to repeat that the committee did everything it could. I know they did. The fact that their efforts, as much as they were, could be foiled by the persons in opposition to my appearing there is the reason why we need very strong advocacy.

**The Chair:** Thank you very much. Please stay on the line.

This committee will recess while we move back to committee room 1.

The committee recessed at 1405.

The committee continued at 1415 in committee room 1.

**The Chair:** I call this committee back to order. Mr Mancini.

**Mr Mancini:** Mr Chairman, I raised a point when we were adjourning from the other room, and this concerns me a great deal. The last witness seems to have had the opinion that we did not have the authority to have him appear before us. As we all know, that is incorrect and I do not think we could leave that on the public record. At the very least, some kind of communication should be sent to this person and to the institution outlining the authority this committee had to have that person appear.

I do not think it is appropriate for all of us to sit in this committee chamber, silent, with our mouths closed, when part of the public believes that we are lacking in some authority that we all know we have, no matter what the circumstances are. If the circumstances are that the Legislature had to be in session for us to get the Speaker's warrant that was talked about, then that should be explained and fully disclosed. For us to do anything less, in my view, is irresponsible. So I look to you, Mr Chairman, for some kind of guidance on this and maybe for some help from the committee members who have been silent through this whole process and wanted to let that ride. I am not going to let it ride, because it is not factually correct.

**Mr Morrow:** Just before we go to the people who are presenting, was there not an all-party agreement on that letter?

**The Chair:** The subcommittee did meet on several occasions and we had great difficulty in trying to determine

what we were going to do with this particular witness. The subcommittee did agree that we would not go the route of a Speaker's warrant.

**Mr Morrow:** So there was an agreement then, Mr Chair?

**The Chair:** Yes, there was.

**Mr Mancini:** Mr Chairman, Mr Morrow is confusing the issue. The issue is not what the subcommittee agreed upon; the issue is the authority of this legislative committee and other such committees. That is what is at issue, not what the subcommittee agreed upon. If the subcommittee did not agree to issue a Speaker's warrant, that is one thing; for the general public to believe we do not have the authority to issue a Speaker's warrant is something altogether different.

I think it is irresponsible of this committee to have the person we heard from believe this committee did not have the authority to issue a Speaker's warrant, when in fact we do. We need to explain to that person the circumstances as to how and when and why we can issue one. That is what I want to clarify. What the subcommittee agreed upon has nothing to do with this issue.

**The Chair:** It is my belief Mr Hardy was made aware that we did have the power to do a Speaker's warrant. If it was not personally conveyed to him by the clerk, then I am sure the clerk would take it upon herself to contact him and let him know.

**Mr Mancini:** No, Mr Chairman, that is not good enough. We clearly heard the witness less than 15 or 20 minutes ago say that he thanked this committee for "doing all it could to get me before this legislative committee." He said: "I don't blame you, I blame this institution. You tried, and isn't it sad that the legislative committee couldn't override two people in this institution."

The person firmly believes and everyone he is in contact with will firmly believe and the record will show and will lead other people who read the record to believe that this committee had no such authority, when in fact we did. I am not saying a Speaker's warrant should have been issued. I am not taking any issue with what the subcommittee decided or did not decide to do. That is not the issue here. The issue is whether or not we had the authority to issue a Speaker's warrant, get the witness before us, how it could be done, when it could be done and everything that revolved around that.

Frankly, it is irresponsible of us to sit here silent and pretend that we did not hear those words and that we could not issue a Speaker's warrant. Whether we want to or not is a separate issue, but surely we have to put that issue to rest and we have to clarify the matter for the public record.

**The Chair:** I think that clarifies the record now.

**Mr Mancini:** It clarifies the record—

**The Chair:** I am in your hands. What would you have us do?

**Mr Mancini:** It clarifies the record for us sitting around this table. It does not clarify the record for the witness and for whoever will come into contact with the witness or whoever will read his portion of the transcript. I suggest that a letter be sent to the witness outlining how a

Speaker's warrant is issued, why one was not issued in this case and what authority this committee has or does not have. That is what is needed, Mr Chair.

**The Chair:** Would you like to put that in the form of a motion, Mr Mancini?

**Mr Mancini:** I do, and I so move.

**The Chair:** It is moved by Mr Mancini that we write a letter to Mr Hardy explaining the process for a Speaker's warrant and the process we went through and why we decided not to.

**Mr Mancini:** If you want to include that, that is fine with me, but surely we have to clear the record.

**The Chair:** The process.

**Mr Mancini:** We have to underline the process. If there is anyone in this Legislature who should believe in the integrity of the process, it should be a number of people I have faced over many years.

**Mr Winner:** I do not have any problem in principle with Mr Mancini's suggestion that we outline the terms and conditions of a Speaker's warrant. I would just like to say for the record that I think it is a little late in the day for Mr Mancini to raise this. He could have brought a motion for a Speaker's warrant earlier and he chose not to because there had been a constructive dialogue among the members of the subcommittee with the conclusion that a follow-up letter of support for Mr Hardy's application to leave the institution would be reasonable and appropriate under the circumstances.

Now, after Mr Hardy has already given his testimony by videoconferencing, I think it is an inopportune time for Mr Mancini to raise this point. I do not think it is constructive and I do not see what gain there is in doing it, but if it will make Mr Mancini happy, I will reserve any objection I have.

**Mr Morrow:** I too will be supporting the motion. The subcommittee had met and had decided that in our time frame we could not get a Speaker's warrant. I believe that was the reasoning. I will be supporting your motion, Mr Mancini, although I agree with Mr Winner and would have hoped it would have come earlier.

**Mr Mancini:** I am surprised that Mr Winner, a person trained in the law—maybe that is one of the difficulties, I do not know. A person skilled in the law, a person who has maybe as much expertise as anyone else on this committee on the issues we are facing—for him to want to deliberately confuse the issues, to me, is very surprising.

I said during my explanation that whether or not anyone on this committee would vote for the Speaker's warrant is not at issue. What the subcommittee decided to do or not to do is not at issue. What is at issue—and I watched you listening very attentively to our witness—is that person believed something other than the truth. He believed, and said so, that this committee did not have the authority to do exactly what we have the authority to do.

He said two people in his institution overrode this committee. That is what he said. For us not to want to clarify that and for members of the committee to want to confuse that with whether or not the subcommittee or Mr

Morrow or Mr Wilson or anyone else on this committee would vote for it is really irresponsible.

**Mr Winner:** On a point of privilege, Mr Chair: If anyone is obfuscating or confusing the issues, it is Mr Mancini, because he knows well—

**The Chair:** That is not a point of privilege, Mr Winner.

**Mr Winner:** Point of order, then.

**Mr Mancini:** That is not a point of order either.

**Mr Winner:** On a point of order, Mr Chair: He knows well that Mr Hardy was satisfied with the efforts of this committee to get him here. He may not have known that the two Conservative members of the committee objected to paying his costs to get him here, but on the whole he was pleased with our efforts.

**The Chair:** You do not have a point of order, Mr Winner.

**Mr Mancini:** Since there is no point of order, can I have the floor back?

**The Chair:** Mr Mancini.

**Mr Mancini:** Mr Winner does not know the rules of the legislative proceedings either. He does not know when he is out of order. He does not know what a point of privilege is. Sir, you heard our witness say—

Interjections.

**The Chair:** Order, please. Mr Mancini, on the motion.

**Mr Mancini:** Thank you, Mr Chairman, you are doing a good job.

Mr Winner, you heard our witness say he believed we had done all we could. You heard him say that. You heard him say there were two people in the institution who overrode the powers of this committee. You heard him say that. That in fact is not true. For us to leave that as part of the record is very wrong.

I hope, Mr Chair, that we could get on with the motion without further obfuscating what the issue is.

**Mr J. Wilson:** If it is my turn to speak and there is no debate, I call the question.

**The Chair:** No. Mr Sterling was next on the list.

**Mr J. Wilson:** He is calling the question.

**The Chair:** All those in favour of calling the question?

**Mr J. Wilson:** I do not know. We had better give him a chance.

**Mr Sterling:** That is what I was going to do.

**The Chair:** All those in favour of calling the question? Opposed? I call the question on Mr Mancini's motion. All those in favour? All those opposed?

Motion agreed to.

**Mrs Sullivan:** I would like to place the motion I put before the committee this morning. The clerk has a suitable number of copies for the committee.

**The Chair:** Mrs Sullivan moves that:

"Members of the standing committee on justice recognize (a) that Bills 74, 108, 109 and 110 are complex, inter-related pieces of legislation, whose principles are broadly supported; (b) that representatives of health care profes-

sionals and practitioners, consumer organizations and agencies, and advocacy groups have advanced reasoned, serious and objective criticisms of the bills, and put forward proposals for their improvement and practicable implementation; (c) that the government has put forward no proposals for amendments to the bills in a public forum and provided no commitments regarding consultation on review of any amendments.

"Therefore, be it resolved that the standing committee on justice advise the respective ministers that it recommends:

"1. That Bills 74, 108, 109 and 110 be withdrawn from active legislative consideration, and be considered as draft bills;

"2. That the bills be reprinted with the government's proposed amendments;

"3. That the redrafted bills be circulated for public analysis and comment during the spring 1992 session;

"4. That a renewed period of public hearings on the redrafted bills be conducted by the standing committee on justice during the summer 1992 intersession;

"5. That clause-by-clause consideration of the redrafted bills be conducted by the standing committee on justice during the summer 1992 intersession;

"6. That the bills proceed to committee of the whole House in the autumn 1992 session."

In fairness to our presenters, do you want to discuss this now or put it over until after our last presenter this afternoon?

**Mrs Sullivan:** We would prefer to proceed now.

**The Chair:** Discussion?

**Mrs Sullivan:** The wording of the motion is virtually self-evident in that it is very clear from discussions before the committee that the preamble of the bill is a fair representation of the situation in which we find ourselves: clear approval in principle on the nature of the legislation, and clear serious concerns and objective criticisms about the specific content and drafting of the bills and the effect they will have if implemented in their current forms.

We know that many groups and organizations have expressed very serious reservations because they have not seen the intent of amendment, although there has been an indication from the ministers involved before the committee that amendments will be coming forward. There was a very clear determination in a response from the parliamentary assistants at our last session that there would be no further public consultation or review subsequent to the amendments.

We are very concerned that these pieces of legislation will affect every single individual in Ontario. They will affect every single family. They will affect every single health provider operating as a professional. They will affect every single person whose vulnerability we are concerned about.

1430

We have had public hearings that have indicated a controversy that is deeper, although less public, than the controversy associated with Sunday shopping. There are serious legal, ethical and moral concerns about these bills, but even more than that, there is serious concern about the effect of these bills if and when implemented.

We believe in a process for reconsideration of the bills so that government amendments can be put on the table,

through the process which is presented here, so that there can be additional public consideration, so that suggested changes and concerns relating to those amendments can be put very clearly before the committee again. The process we are recommending is indeed an appropriate, streamlined process which follows the rules of the House and ensures there will be consultation that will lead to some greater concurrence on the redrafted bills. We believe this is reasonable.

I think we have made it very clear—our party and the third party—throughout these hearings that there is no disagreement on the principles of the legislation. Where there is disagreement is on the particular approach in the drafting, on the costs associated with it and on the lack of information that is being put forward. We believe this is a process through which all those areas can be explored with the full information of the government's intention. That is why this motion is on the table. I urge the committee to accept it, and we will be pleased to cooperate as this new process moves along.

**Mr J. Wilson:** Before we give fuller comments on the motion itself, I have a question to the parliamentary assistants present that pertains to the motion. When are the government's amendments coming forward and how substantial are those amendments? We did have a cancelled subcommittee meeting at noon today in which we were going to hash out some tentative dates, so I would like a response to that question.

**Mr Malkowski:** I think first what we need to say is that we are not finished with public hearings. We need to finish the rest of the afternoon and then we need time to review those presentations.

**Mr J. Wilson:** That party, the NDP, does not seem to understand that these legislative committee hearings are not their public hearings, as the public understands public hearings. These bills have gone through the House and received second reading. These hearings traditionally in parliamentary procedure have been used to fine-tune legislation, and what we have been hearing from witnesses is that there has to be a major overhaul of this legislation for it to be acceptable.

I think it is incumbent upon the government to bring forward amendments, rather than have witness after witness repeat a number of points that are brought forward and each time have the parliamentary assistant say, "Well, don't worry about that because we're bringing forward amendments." You are going to waste a lot more time and taxpayers' money if you do not bring forward your amendments before these hearings end today. Let us know exactly what you are intending to amend. Otherwise we are going to be recessing. We are all going to go back to our respective caucuses, get our research departments working overtime to draft similar amendments and duplicate efforts, when it would have been a lot easier if the government had brought its amendments forward and not used these legislative committee hearings as public consultation. That should have been done months ago before these bills were drafted and presented to the House, in my opinion.

**Mr Winner:** I just want to say briefly in response to Mr Wilson's remarks that he is beginning to sound like a broken record, because we heard this on day one and we heard this on day two and so on.

**Mr J. Wilson:** At least I am consistent.

**Mr Winner:** I think the message has gotten out to the public that we want to hear from everyone before we review the amendments that have to be made.

**Mr J. Wilson:** That is a political spin you have put on this.

**Mr Winner:** Some people have said that fine-tuning is required here, not a major overhaul. If we are going to take these recommendations at all seriously and improve the legislation, which to my mind is the purpose of the sitting of this committee, then we have to do just that. If we move prematurely on this matter, then we are going to waste the kind of time and money Mr Wilson just alluded to. So I am afraid that Mr Wilson and I cannot agree.

**Mr Sterling:** I would like not to support this, but I am being put in a position where I must support this motion, because notwithstanding the scolding that Mr Winner has given Mr Wilson, the fact of the matter is that Mr Wilson's position and the position we have taken on this side has been continually supported and buttressed by witnesses who have appeared in front of this committee. Therefore, I find myself in a very difficult spot, because we wanted, and I continue to want, to be constructive, but without the government making any move, in spite of the overwhelming amount of evidence that has been placed in front of us, without it showing its hand at all, I am not certain it is able to fix up the legislation to meet the arguments of the witnesses.

If they could demonstrate to me that they can meet what has been brought forward, that they have sat down and thoughtfully put forward a number of major amendments which will address the very significant concerns on these bills, then I would be tempted to vote against this particular motion. So I leave it open to you, the government members. Are you willing now to put down on the table what you are planning to do? We are getting very close to the end. I would have preferred to have this motion discussed at 3:30 after these people and other people have made their presentation.

**Mrs Sullivan:** I think perhaps we could hear from the parliamentary assistant for the Minister of Health.

**Mr Wessinger:** I would like to say with respect to this motion that certainly as far as the bills are concerned, I consider that we are going through the normal legislative process here. I would also like to assure members that it is certainly the intention that with any amendments that are presented, the opposition will have ample time to review those amendments.

I know the Conservative members indicated concern about whether they have to get their research staff started on doing their own amendments. I would like to assure them that I would certainly like to continue working in cooperation with respect to the bills. Certainly it is the intention to give ample time for them to examine any amendments that are put forward, but at this stage we are not really at the stage of putting forward amendments. I

would like to assure the opposition that it is the intention to have ample time to look at the amendments that are made so they can do their appropriate response to them.

**Mrs Sullivan:** I would like to point out that this is not a normal consideration of a normal, average piece of legislation. We have been discussing in this committee six bills, four of them put forward by the government, all of them interrelated, all of which require consideration of their interrelationship one with the other, all of which affect, as I have indicated, every individual in the province, not a small sector.

This is not a normal, average, routine situation. I am astonished that the parliamentary assistant for the Minister of Health considers this to be a routine matter. We are dealing with changing common-law issues that have been common law for hundreds of years and whose evolution has changed substantially in the past 30 years. Now we are attempting to codify those common-law issues along with new concepts that have evolved and become socially desirable in the past 10 to 15 years. This is not something that is easy, straightforward and simple. This is very complex.

We are asking that the government bring forward its amendments and commit to a period of time for analysis and comment, so that we can go back into a renewed public hearing process on the redrafted bills, to hone those bills and ensure they become workable. I do not understand why there is any objection to this motion and I am astonished that the parliamentary assistant believes this is a matter of some simplicity.

**The Chair:** Further discussion on the motion?

**Mr Morrow:** I believe you are going for a vote at this moment.

**The Chair:** I was about to call the question.

**Mr Morrow:** First of all, I would like to apologize to the witnesses who have been sitting here waiting from 2 o'clock, but I would also ask for a 10-minute division.

**The Chair:** A 10-minute division; we will resume at 2:51.

The committee recessed at 1441.

1451

**The Chair:** I call the committee back to order.

**Mrs Sullivan:** Mr Chairman, I request a recorded vote.

The committee divided on Mrs Sullivan's motion, which was negated on the following vote:

#### Ayes-5

Mancini, Poirier, Sterling, Sullivan, Wilson, J.

#### Nays-6

Carter, Ferguson, Morrow, Wessinger, Winninger, Malkowski.

**The Chair:** We will now proceed with our schedule.

First of all I would like to welcome to the process the University of Toronto students in attendance today. This is a necessary process. I apologize to our witnesses who have waited patiently.

#### MARJORY M. CAMPBELL

**The Chair:** Our next presenter is Marjory Campbell. I just remind you that you will be allowed a half-hour for your presentation. The committee would appreciate it if you would keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. Could you please identify yourself and your guests for the record and then proceed.

**Mrs Campbell:** My name is Marjory Campbell. I speak as a private citizen and as a long-term mental health consumer. Due to illness Ms Golightly is unable to be with us today. In her place I am pleased to have with me Mr Rick Dafoe, a fellow consumer who has suffered from the same disorder as she, and my husband, Mr James Campbell.

We wish to thank you for this opportunity to present a further viewpoint from among those who would be most deeply affected by the implications of Bills 74, 108, 109 and 110. We are proud to be part of a society whose elected representatives invest so much time and energy in pursuing justice for citizens who are at a relative disadvantage compared with the majority. The theme of this brief, taken directly from the Canadian Mental Health Association's 1991 national conference, is Partnership for Change.

As I said, I speak as a consumer. I should like to narrow this further. I am not qualified to speak of consumers who become such because of deep-rooted social and/or emotional problems, nor even of those who suffer or have suffered from the milder forms of major psychiatric disorders.

Because of the nature of my own experience over the past 11 years, and because this is what the Graham report strongly suggests we all do, I shall concentrate on those who, like myself and Rick, are afflicted with serious to severe forms of psychiatric disorders. We suffer respectively from bipolar affective disorder, until 1983 known as manic-depressive illness and schizophrenia, each of which is reported to affect one out of every 100 people in the population. The effect of these disorders is that our brains function at full capacity some of the time, yet are at odds with reality at other times. You can imagine how fraught with difficulty our interpersonal relations become at times for us, for our family members and for thousands of similarly affected families across the province.

**Legislation:** It is largely because of the increased fragility of our closest relationships that many of us consumers have concerns about the Advocacy Act as it is presently before us. We agree that given certain amendments, a percentage of the disabled could benefit from the services of a roving advocate. Those are vulnerable persons with no trusted family members and no trusted non-family significant others. This relatively small minority, whether psychiatrically or otherwise disabled, is especially vulnerable. We feel particularly for those vulnerable persons whose parents have abandoned them as children because of a serious developmental or mental handicap.

However, Rick Dafoe and I and most of our consumer friends wish to state emphatically that we desire to continue discussing our options with significant others: close family members and/or fellow consumers and/or trusted health professionals.

1. Rights of entry: We see no need for another third party, the advocate, whose rights would not end at his or her office door but would extend into our and our family members' inner sanctum, our own home. Such unwarranted invasion of privacy could, and we are pretty sure would, in a significant number of cases wreak permanent havoc on family relationships already threatened by the effects of a serious psychiatric disorder. And who is to protect the advocate if, as could happen, actual violence broke out at or in the home?

We must not swing the pendulum all the way from ignoring the vulnerable and our rights to treating us as more important individuals than our family members, our doctors etc.

2. Access to records: Speaking of rights, a third party, the advocate, ought to have no more rights of access to a vulnerable person's medical records than does (a) the vulnerable person and (b) the significant other, if the former is incompetent. Those rights should depend upon the consent of the vulnerable person.

The proposed invasion of privacy here in sections 24 to 28 is as intolerable in a free society such as Canada as is the proposed right of entry into a vulnerable person's home. We suggest therefore that subsections 24(1) and 24(2) be retained and that subsection 24(3) be removed. The decision whether or not to see his or her clinical record should be that of the vulnerable person alone except when he or she is incompetent.

The present legal position, that even when we are not in their care only doctors' authorizations can enable us to see our own records, is quite unjustified and undermines precisely the partnership which the majority of psychiatric consumers is trying to build with health practitioners.

3. Incompetence: It seems clear, from the definition in section 2 of "vulnerable person," that whoever drafted it likely has never experienced a state of mental incompetence, for a key verb is missing. As one who was rather frequently and quite unpredictably incompetent during the 1980's, may I point out that the real tragedy is not so much in "expressing or acting on his or her wishes" as in formulating his or her wishes in the first place. Once seized upon by a brain whose neurons etc are whizzing around all wrong, those wishes later often turn out to have been against one's own best interests; for example, my wish in 1982, expressed to a lawyer, to have my husband of 11 years no longer be my next of kin; my unpremeditated wish to be dead during inexplicable, excruciating depressions and two out of six or seven attempts that almost cost me my life; the decision of Gallagher, of *Fleming v Gallagher* fame, to remain incompetent rather than try medical treatment again.

So, ladies and gentlemen, we are puzzled. I and others who have been similarly placed would ask you, how could an advocate or anyone else present a set of options to a person whose brain is temporarily or permanently out of commission? Should it happen to me in the future, I want the brain of the significant other, my husband, to be able to act and lawfully make decisions on my behalf. Love and care often win out in time. Discussions of rights and options have no chance.

We believe therefore that our best hope in the situation of incompetence remains a good working partnership between our significant others and our health practitioners. Those of us whose period of incompetence will pass, the majority, will return to play our lead role in that partnership in due course. After that perhaps an advocate whom we choose to see, or telephone if too disabled or too poor to travel, could be of service to those living alone with a serious disorder. We could all certainly do with a patient advocate service in each hospital, not just in the 10 provincial psychiatric hospitals.

4. Qualifications and training: A major weakness of this well-intentioned act remains its failure to attempt even the broadest definition of the prerequisites to becoming an advocate in the new sense. This is not something we vulnerable persons, our families and our health practitioners wish to leave to the Advocacy Commission or the appointments advisory committee.

In our opinion it is for us to suggest and for our legislators to set down to be seen clearly the criteria for such a sensitive and responsible position before the passing of the act. We are particularly concerned about the quality and length of training that will be available and required to assure us of a future advocate's ability to judge major complex issues; for example, whether a vulnerable person's open or disguised antagonism towards a family member or health practitioner is founded in reality or is a feature of a clinical disorder.

5. Appointments advisory committee: If an appointments advisory committee is to be established it must represent us all. So far, section 15 makes no sure provision for representing those under 65 years of age who are temporarily or indefinitely incompetent due to psychiatric disability. This needs to be rectified.

If the majority of you remain convinced that all psychiatrically vulnerable persons need advocates, why not look to the present fairly effective system of patient advocates in the 10 provincial psychiatric hospitals as models. The proposed advocate could be located somewhere public and accessible, for example at the public hospital most central to the advocate's area, for part of the day. During that time vulnerable persons, or where they are incompetent their family member or significant other, could access that advocate by phone or in person.

A great deal of time, money and above all, anguish would be cut out if psychiatrically vulnerable people in the community were invited to make that contact when needed. Our greatest source of empowerment, after all, is in regaining self-motivation. If the family or society babies us, we could remain disempowered and hence vulnerable indefinitely.

6. Hospitalization: Time and the complexity of the issues, particularly as they relate to major psychiatric disorders, constrain me from commenting in detail on the Consent to Treatment Act. In my own case of severe bipolar affective disorder, I am in no doubt that without the emergency room in the local hospital I would be dead and that without the multifaceted, multidisciplinary approach of the nearest provincial psychiatric hospital I might have had less quality of life restored.

So, yes, I believe we need to retain involuntary hospitalization. For the first three years, at least, many of us have trouble believing there is something wrong with our brain. It is always somebody else's or even everyone else's brains that seem out of sync at the beginning of an illness. To prevent abuse we need to keep the very stringent laws that apply under the 1978 Mental Health Act and to ensure that they in turn are not abused.

7. Medication: We need to make sure too that once hospitalized it is impossible for the consumer to be over-medicated. A report in the late 1980s alleged that 25% of Ontario doctors overprescribe. If this is true it is intolerable. I suspect that some part of this overprescription may be going to the elderly and to consumers in non-specialist hospitals; hence the need for an act such as this.

If it is impossible to obtain the consent of a psychiatric consumer due to incapacity, I am not convinced that a medical emergency will ensue if anti-psychotic drugs are withheld for a limited time. Take my own case as an example. Apparently in April 1983, while resident in a provincial psychiatric facility, I went into a psychosis more profound than any I experienced before or since. The calendar had certainly moved on 12 days when I recovered. Apparently I refused all food, water and medication. The psychiatrist had the wisdom and courage not to prescribe intervention but to let nature take its course for a time.

When I came to, he told me that very day he had had my closest family members sign a form authorizing electroconvulsive therapy and that he was on the point of sending me to the facility's infirmary for forced feeding, as starvation and dehydration could not have continued for much longer. Obviously, then, there must be a limit at which point a doctor must have the right, with the consent of significant others if possible, if not, then without consent, to intervene to save a patient's life or sanity, for as Dr Bessie Borwein remarked in this room on March 10, "The freedom to be insane is an illusory freedom." I would add, ditto the freedom to be dead.

8. Physical illness: Bearing this in mind, I must say that with regard to purely physical illness such as strokes and heart attacks and to the results of accidents or suicide attempts, I believe the health practitioner is too much restricted by clauses 22(1)(b) and (c). I think that the phrase, "likely to suffer serious bodily harm in twelve hours," clause 22(1)(b), should be amended to, "could suffer further bodily harm within forty-eight hours," and clause 22(1)(c) should be brought into line with that. I do not know about you, but I would rather take the risk of intervention than that of the health practitioner being in error regarding the time when "serious bodily harm" might occur.

Last, if I am ever again incapable for whatever reason, I want to be free of all that is superfluous to recovery. I do not want advocates worrying me, or for example the elderly incapable, or my family or my doctors. We are, as I said, a partnership, though one or two earlier health practitioners I had were unwilling and/or unable to play their part in that way.

9. Forms: Please let me know if, when and in what form this legislation is passed so that I can speedily take

the necessary legal action to preserve this partnership, and please make the new form big enough. There is not space on the present form 44 to set down either the name and address of your second substitute, to borrow a phrase from soccer, or the details of the treatment you do or do not wish to be given.

10. Thanks: We would like to express our gratitude to the present government for bringing forward this proposed legislation, to Mr Norm Sterling for his invaluable work on Bills 7 and 8 and to the previous government for commissioning the Graham report, 1988. We would also like to thank our MPP, Brad Ward, his Queen's Park office and his constituency office for all its help in this matter. Finally, we would like to thank you all for listening.

**Mrs Sullivan:** Thank you very much, Mrs Campbell. I know that you have been an active participant in the hearings, following very much and very closely the issues that have come before the committee and that have been a matter of consideration. I know from other conversations you have had not only with me but with other members of the committee that you are very familiar with the bills that are here. I think you have presented a very poignant and articulate brief to us.

I think one of the things that really struck me about your brief, and that has come home from many of the briefs of the health care professionals, relates to the balance of statutory rights, civil rights, versus the balance that has to be given to the right to health care, which in fact preserves other rights. If you have underlined anything for us today, that issue has come very much forward.

I was also taken with your comments relating to training, and I think that is one of the things that we want to press the government for further information on. I do not have any questions. I liked your brief.

**Mr J. Wilson:** I too thought it was an extremely articulate and well-presented brief. There is very little in it that I would question. I gather, just for clarification, that you would prefer to see the current patient advocate system perhaps expanded and that advocates really should be on call when needed. I guess the question that raises in my mind is, when individuals are in a psychotic state, are they from time to time aware enough to call an advocate if they need one?

**Mrs Campbell:** They might be, but I think the more likely person to speak to would be the family member or the health practitioner. These are really the only two people you feel you want around you because you want out of that condition as quickly as possible. All my relationships with patient advocates have been while out of hospital. At no time when I was in was I ruminating on things like rights, nor were they removed from me to such an extent that I felt I had to.

1510

**Mr B. Ward:** I would like to thank you as well for your excellent presentation. I think, when there are not very many questions from the parties represented on the committee, that you have had a very thorough presentation. What is important to recognize is you based your presentation not only on your research that you have done

into this area but on your own life experience as well, and I think that type of information is invaluable for this committee to consider as the legislation is discussed now and in the future.

I do have one question, though. On page 4, section 5, appointments to the advisory committee, you mentioned that there is an apparent omission in the makeup of the proposed appointments advisory committee. Marjory, I was wondering if you had given any thought to how you would propose to represent those who may be incompetent on this committee.

**Mr Campbell:** I notice that the grouping we fall into is the grouping with both psychiatric and emotional illness involved. I think that Rick and the others would most likely agree with me if I said that we who have been psychiatric patients have great experience of emotional problems because that kind of illness causes emotional problems. I would suggest that it would be better to have a representative from an organization which oversaw the needs and requirements of psychiatric patients rather than to have a person from an organization that did not deal with emotional illness, because normally they would not be prone to psychosis and therefore would not have any members who could comment on that state of incompetence.

**Ms Carter:** Just a quick comment and a question: First of all, you said that we left the training and who was to be advocates and so on vague and you wanted that set out definitely. We deliberately left that vague because we wanted the people who would be on the Advocacy Commission and who would be chosen by this group that is set up in section 15 of the bill to be speaking from firsthand knowledge of what they wanted and so on. So that was deliberate; that was not just fuzzy thinking.

The other thing is, you see the advocate as a third person.

**Mrs Campbell:** Oh, yes.

**Ms Carter:** You see a vulnerable person who has a caring spouse and care givers and so on. What about the person to whom the advocate is a second person? That is really what is behind what we are doing. I mean the impetus behind this act was what happened at Cedar Glen, where somebody who was totally unprotected was ill-treated and died. What are your thoughts on that?

**Mrs Campbell:** I tried to make it clear in the brief that we are completely behind the idea of supporting advocates for persons who are on their own. In that connection, all disabilities, not just psychiatric, but all persons dealing with anything that could make them vulnerable on their own would probably come to be included. But why I thought they would not come to be regarded as really close to you is because my understanding at another hearing was that there were going to be only 150 for the whole province. I think the need is so great that we could use 150 in Metro Toronto.

**Ms Carter:** But of course there will be volunteers, some of whom are already in the field, and there will probably be more.

**Mrs Campbell:** Additionally to the 150.

**Ms Carter:** But I think we see the act as principally applying to and being for those people who do not have caring others. We are not seeing them as somebody who butts in on a situation which is already viable.

**The Chair:** Mrs Campbell, Mr Campbell, Mr Dafoe, on behalf of the committee, I would like to thank you for taking the time out this afternoon and giving us your presentation.

I would like to call forward our next presenters, the Council on Aging for Lanark, Leeds and Grenville Counties.

**Mr J. Wilson:** Just in the interim, perhaps we could ask, then, if the government's intention is that this system not interfere in family relationships and in support structures that are existing, why is the legislation written so that the advocates are a mandatory part of the new system? Perhaps one of the parliamentary assistants would like to respond to that.

**The Chair:** Is there a response?

**Mr Malkowski:** I was not watching. What was the question? Can you say that again, please?

**Mr J. Wilson:** The point has been made time and time again by some of the government members that the intent of the legislation is not to interfere in vulnerable persons' lives where family structures already exist and support structures already exist, that advocates really are not intended to interfere in those existing structures. So why is the legislation formed so that it makes advocates a mandatory part of the process? The previous presenter suggested that perhaps advocates really should just be on call when vulnerable adults require them, whereas I read there is a mandatory requirement for advocates in parts of the legislation.

**Mr Malkowski:** Can I refer to legal counsel to respond to your question?

**Mr J. Wilson:** Sure.

**Ms Spinks:** Are you referring to the rights advice function under Bills 108 and 109, which is a mandatory intervention?

**Mr J. Wilson:** It is also mandatory when you go to guardianship and a number of other aspects.

**Ms Spinks:** Right, but I think you are referring to the mandatory rights advice requirements under the other two bills, because there is nothing mandatory about advocacy under Bill 74. I think that, to be brief, the purpose of the rights advice function is to ensure that there is an independent, informed party providing that narrow description of what an individual's rights are. I think you probably agree it would not be appropriate to sort of have a family member expected to perform that function in a medical setting.

**Mr J. Wilson:** In that case, then, it is simply a rights advisory function? It is not what we hear from witnesses as the full meaning of advocacy?

**Ms Spinks:** I do not want to minimize the role of an advocate in providing services to an individual under Bill 74 or in doing systemic advocacy under Bill 74, but with respect to the other two bills, I think that if one looks at the

sections that describe what an advocate is supposed to do, it clearly is explaining to him the effect of what has happened, which is generally the finding of incapacity and the fact that they have a right to appeal.

ADVISORY COUNCIL ON AGING FOR LANARK,  
LEEDS AND GRENVILLE COUNTIES

**The Chair:** Good afternoon. Just a reminder that you will be given a half-hour for your presentation. The committee would appreciate it if you keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Ms Diakun-Thibault:** I shall try to do my best. My name is Nadia Diakun-Thibault. I serve as the executive director for the Advisory Council on Aging for Lanark, Leeds and Grenville Counties.

"If a man will begin with certainties, he shall end in doubts; but if he will be content to begin with doubts, he shall end in certainties." Bacon's philosophical caveat is worth bearing in mind. Legislation should not be written in isolation from reality. What may appear to be reasonable today, in time, after careful consideration, will no longer hold the promise of solution.

On advocacy, there is no doubt that there is and always will be a segment of the population that will have need of advocates, whether informal or codified. But which definition of advocacy and advocate should we use to guide us in interpreting Bill 74?

What is understood by "vulnerable person" for the purposes of the act is defined, albeit in part. We submit that everyone, members of the committee included, at some point in time, for however brief it may be, will be vulnerable. But if we apply stricter parameters to the definition and argue that those vulnerable persons whom we wish to protect are those who will have continued difficulty in expressing their wishes and will have a disadvantage for longer stretches of time, then there is certainly an understanding of durability of situation.

As for the definitions of "advocacy" and "advocate," referring to a standard legal dictionary will give one interpretation. But law dictionaries are not generally found on the shelves of an average Canadian home. The understanding and interpretation is rather simple and might contain words like: "representative; someone who works for the public good and general welfare; bring issues before the government on behalf of seniors," words which fall in the ambit of a journalistic definition.

This committee has heard representations from many organizations which would not consider themselves lobbyists for change, but certainly advocates on issues that concern their constituencies.

Ontario jurisprudence does not recognize advocacy as a charitable purpose. It is seen as a political activity that non-profit charitable agencies may not engage in. What this bill proposes in effect would or should halt any further letters patent granted, and should or would prompt the review of many letters patent already registered. The former is probable; the latter would be an imprudent public

relations exercise for politicians. Is it truly possible that the Attorney General would run around and strip religious institutions and the United Way of their charitable status?

1520

By virtue of the democratic nature of our society, we assemble, join forces and become proactive. What one generation would have labelled "civic duty," another now calls "empowerment." Empowerment somehow suggests that vast numbers of Canadians have become disfranchised, non-citizens, an unprotected body politic without any hope or means of exercising rights protected not only by the charter but by common-law heritage and practice.

Bill 74 sanctions activities called "advocacy services to help vulnerable persons to bring about structural changes in the political, legal, social, economic and institutional levels." Perhaps legislators view this passage differently than the layman citizen. But is this not a contradiction of principles and philosophies? Is it possible for the government to bring about legislation that will codify civic duty and responsibility, that will effect economic change, that will virtually regulate our individual implicit responsibilities to community and society as a whole?

It is difficult to change social mores; it is difficult to bring about enlightenment in society; it is difficult to educate everyone and ensure universal broad-mindedness, if you will.

Over the years our attitudes and behaviour towards vulnerable people have changed. We no longer believe that physical incapacities diminish the self-worth and potential contributions of any human being. We no longer believe that physical barriers cannot be overcome; technology has disproved that. And we no longer hold pity for vulnerable people, but rather strive to adjust the physical world to ensure mobility and integration of people who may need assistance.

The proposed legislation has many flaws:

1. It sets no limits to the powers of advocates and to the term of application on a case.
2. It takes upon itself the herculean task of taking cultural, religious and other traditions into account as if it were child's play.
3. It paves the way for potentially uncontrolled, unlicensed and unaccountable advocacy services.
4. It protects advocates from damages litigation.
5. It contradicts the rights of non-profit charitable agencies beyond the presently accepted scope.
6. It ensures the potential for abuse by overzealous individuals by not limiting powers of entry and penalizing anyone who may deny entry by presuming guilt. What really does constitute "reasonable grounds"? Will we have to wait for the courts to decide, should this legislation come into effect?

Although the spirit of the legislation may be laudable, needs, real or perceived, do not necessarily justify the establishment of unlicensed advocates.

"Seniors who appear most vulnerable to consumer fraud are those who are frail, who suffer from sensory loss and possible intellectual impairment, who are socially isolated, who have minimal education and deficient literacy and communication skills and who are in need of services

to maintain their independence in the community," according to the National Advisory Council on Aging.

The council, in a publication entitled *Consumer Fraud and Seniors*, published in March 1991, listed a number of proposed factors that make certain seniors more vulnerable than others: (1) a lack of consumer information; (2) diminished sensory acuity and slower rate of assimilating information; (3) a lack of wariness in commercial relations; (4) social isolation; (5) a lack of self-confidence, and (6) a greater need for certain services and products.

Studies have shown that "in comparison to younger adults, elderly consumers tend to be less aware of unethical practices, more tolerant of substandard goods and services and less likely to pursue a complaint even when it is clearly justified."

If we cannot adequately protect consumers, regardless of age, from fraud through existing legislation, what assurance do we have that we will be able to protect vulnerable persons from unscrupulous, overzealous persons who would abuse their positions as advocates? None.

On consent to treatment: We argue that even a university-educated person can have more than ample difficulty in determining the correctness of treatment. There are graduated levels of understanding.

Bill 109, the proposed legislation on consent to treatment, has defects primarily of definition and application; "capacity" and "incapacity" are not adequately defined.

The Fram committee defined capacity in the following terms:

"The ability to make an informed choice is the essence of mental capacity. Mental incapacity means the incapacity to understand information relevant to making a decision or the inability to appreciate the consequences of a decision or lack of a decision.

"Mental incapacity must be defined so that persons who are capable of making a choice or decision will not have these choices or decisions interfered with, even if most members of the community consider them eccentric or even bizarre. 'Capable' would include the ability to make choices or appreciate consequences with the assistance of others. We receive information from explanation and thus we rely on explanation for understanding. Therefore, when a person accepts the assistance of another and is able to to understand a concept that would not be understood, the person is capable..."

The committee recommends:

"Mental incapacity should be defined so that legislation to provide substitute decision-making for persons who are incapable cannot be used to interfere with the freedom of action of persons who know what they are doing and appreciate the consequences of their acts, or can do so with assistance."

It is presumed that the informed decision will be made by the advocate, according to these bills, and it is his informed decision, whatever that means, that should be unquestioned.

Let's suppose that a person is brought into a hospital with a severe upper respiratory infection and it is determined that the person has pneumonia. That person is deemed vulnerable through the process and incapable of

granting informed consent to treatment. The physician follows the steps outlined in Bill 109. An advocate is called in. All the prescribed elements have been followed and treatment is administered, possibly a sulpha drug to fight the infection and aspirin for the fever. What if that incapable person is allergic to aspirin, allergic to sulpha drugs and asthmatic? What medical harm would be done? What if any of you were that person?

On substitute decisions: This bill should give everyone pause to consider relocation to another province. Although it is primarily a bill concerned with the management of property, it has elements that give rise to even greater concern.

They are: section 17, which does not permit family or a common-law partner to be appointed statutory guardian if there is also an application by the attorney under a continuing power of attorney; and section 24, which excludes anyone who is not a resident of Ontario. Many incapable or vulnerable people—people with dementia in nursing homes, for example—may have family who reside in other provinces. For that matter, many families live on both sides of provincial borders—and since I have lived close to Ottawa, we know this is a fact—and there is no justification that such family members should not be allowed to act as statutory guardians of property, for whatever reason.

Section 31 under "Powers of Guardian": The guardian can do anything in respect to property that the person could do if capable except make a will. Apart from the expected managerial duties that a guardian of property would have, there are other powers, such as making charitable donations, provided that it can be proved that the person would have made a similar contribution and has made such contributions in the past. If wishes for charitable donations are made in a will then there is no problem. But there is a problem if there is no will. Then it is up to the guardian to make such decisions. Donations to bogus charities could be made without notice, and once they are noticed it might be too late. There is certainly potential for abuse here and tighter guidelines must be in place.

Section 56 grants guardians full custodial care and it gives them the power to determine the living arrangements. What if the person is cognitively impaired, such as an Alzheimer person? The guardian could insist that the person remain in the home and not be placed in a facility better suited for that person's care. Being home alone for a cognitively impaired person is both dangerous and imprudent. I know this for a fact because my mother has Alzheimer's disease.

Imagine the worst-possible-case scenario: It is your child or your aging parent who has been left because some demise has befallen you and there are no relatives in Ontario to care for your loved one. Would you entrust to a stranger the right of custodial care? Probably not.

Acting in good faith in making decisions on behalf of another human being is a vast responsibility. If the actions result in serious bodily harm, financial damages, further medical problems, even death, why should the advocates and the commission be absolved?

There can be no a priori absolution for those acting under the proposed intentions and spirit of these bills. Although there may be others who would argue in favour

of the bills as drafted, perhaps much more eloquently than I, even so, consideration to extensive amendments must be given. Thomas Jefferson warned that, "No more good must be attempted than the people can bear." We submit that the people will not be able to bear the good this legislation purports to do.

Thank you very much. I apologize for any errors and omissions or typographical errors.

1530

**The Chair:** Thank you. Questions and comments?

**Mrs Sullivan:** How much time do we have?

**The Chair:** About four minutes each.

**Mrs Sullivan:** Four minutes? Okay. I will be quick. I appreciate—and I think all members of the committee do—your appendix, which includes specific reference to the bill. That has taken you a lot of time to put together, and—

**Ms Diakun-Thibault:** May I just say that those are working notes prepared by an advocacy committee or, I should say, a committee charged with looking at these bills, as well as whatever assistance I could provide for them. Those are just draft notes. We would be happy to submit our proposed amendments also.

**Mrs Sullivan:** Great. I think that even the draft notes will be useful to us as each of the caucuses goes about preparing its amendments and the government prepares its amendments. I think that is useful.

I was very interested in many of your comments relating to advocacy. One of the things that is of some concern is the lack of definition of the training, the skills, the competence, the scope of advocacy practices, if you like, the discipline associated with advocacy. I wondered if you wanted to comment on that.

**Ms Diakun-Thibault:** I certainly would like to. As far as we can see, advocacy is not a discipline at this time. Health practitioners are a discipline. Legal advisers, solicitors are a discipline. Even accountants are a discipline. If this legislation were to see some life in the future, then certainly we must consider that advocates, too, should be a discipline and should be regulated and licensed and should be accountable to some body, whether professional or legal.

**Mr Poirier:** Before, while we were discussing Ms Sullivan's proposal, or just before we started to, I talked with Ms Diakun-Thibault and told her that, yes, she may be the second-last person to come forward, but I think her presentation—I told her it was going to be this way, but she confirmed it. The quality of what you did and the type of suggestions that you have, I much appreciated your coming forward with that. Please give our regards to the people who sat down with you to propose this.

This is going to be very helpful for us. It confirms a lot of the fears that we also have, and it goes to show you—we were saying that tongue-in-cheek, but I am saying it seriously now—thank God, even if it is the last day, that you came forward with this. It is most important. Thank you and congratulations.

**Ms Diakun-Thibault:** Thank you, Mr Poirier.

**Mr Villeneuve:** Thank you, Ms Diakun-Thibault. Coming from eastern Ontario, what else would you expect?

**Mr Poirier:** There it is. Right.

**Mr Villeneuve:** It is natural.

**Mr Poirier:** Yes, humble as we are, eh?

**Ms Diakun-Thibault:** Mr Villeneuve is my MPP.

**Mr Poirier:** Our sympathies, in that case.

**Ms Diakun-Thibault:** We share similar sentiments, I suppose.

**Mr Villeneuve:** I am interested in your comments on section 17, where, under continuing power of attorney, a family member or a spouse or a common-law arrangement would be disallowed. Could you comment a little further on that particular area?

**Ms Diakun-Thibault:** My reading is that they would be disallowed for application, and they should be allowed to apply. Whether it would be prudent that they be granted is certainly not a matter that I could comment on today. I certainly would like to take it back to our committee and have them look at it a little more closely.

**Mr Villeneuve:** I have attempted to address problems faced by a certain family in Grenville county with a very, very sad situation with children's aid. I will not go into it any more deeply than that. It was a rather sad case and, whether children's aid was right or wrong, it was terrible. As it turned out, children's aid appeared to have been wrong in their assumption of the reasons they took a child away from its parents. However, in this particular case, I think we ran into some very overzealous people. I see this particular legislation as opening the door for people who would tend to be overzealous. If we designate a discipline for them, it is still going to be difficult to deal with people who are overzealous in their application of whatever power they have, if indeed advocacy becomes a discipline. Could you comment to some degree on that, because in a rural area close to the Ontario-Quebec border that you touched on, I would think in most cases there would be a relative. It looks like it may be difficult to bring in a relative under certain conditions, particularly if legal matters are at stake. Maybe you could comment on that one a bit.

**Ms Diakun-Thibault:** I feel a bit at a disadvantage because I am not a lawyer by training, even though I perhaps have a penchant for legal things. I would like to state that we believe very firmly that if this were a discipline, one with certain guidelines, one with rules and regulations, one which would be accountable, one which would allow the person who may have a grievance against the advocate to litigate, to literally sue the advocate for malpractice the way you can sue a lawyer or sue a doctor or your accountant or anyone who embezzles and is fraudulent—granted it may be very difficult to assure that everything is going to be perfect in a very imperfect world, but none the less—there is some measure of recourse and common sense being applied in the act. As we read the act today, there is none of that.

**Mr Villeneuve:** In your opinion, Nadia, would we be better without legislation than with what we are bringing forth now?

**Ms Diakun-Thibault:** I would like to say that we would be much better without this particular piece of legislation as it is drafted. Perhaps we should look at whether there is clear justification, whether numbers warrant and whether there is an overriding and compelling argument to support the establishment of an advocacy discipline. If there is not, then we need no legislation, but if there is, then we do. But this legislation must not be in the form that it sits before the House today.

**Mr Villeneuve:** By the way, congratulations on being the new executive director of the Lanark-Leeds-Grenville counties' advisory council on aging.

**Ms Diakun-Thibault:** Thank you.

**Mr Wessinger:** Thank you for your presentation. I would like to make one comment with respect to your brief just to clarify the position of an advocate under Bill 109; that is, an advocate does not make decisions under Bill 109. An advocate's role is purely as a rights adviser to advise a person with respect to the question of incapacity.

**Ms Diakun-Thibault:** I stand corrected.

**Mr Winninger:** In response to a couple of submissions you make in regard to Bill 108, and in particular section 17 and section 24, it is quite clear from the wording of section 17 that if there is an application by an attorney under a continuing power of attorney for guardianship, another member of the family cannot apply at the same time. The reason for that, in my view, is that you want to have a guardian who is as authentic as possible. If you can actually have the person who has been appointed by the individual who lacks incapacity to be the attorney, then that will most closely accord with the donor's wishes.

On the other hand, that attorney may be a family member to start with, and in my experience often is, so what you would have is a situation where the existing attorney applies to become the guardian, and he or she could quite easily be a member of the family, and at the same time someone else could not apply. Let's say, for example, that the attorney under a continuing power of attorney applied to the court to be appointed a guardian and was found unfit to be the guardian. That would not preclude a spouse or a partner or a child or a parent then coming forward and saying, "Look, that person wasn't suitable but perhaps I'd make a more suitable candidate for attorney." I wonder if you would agree that the wording permits that interpretation.

**Ms Diakun-Thibault:** Again, I feel very much at a disadvantage because we are now delving into a realm in which I am not personally capable, if you will, and have not the education to address that in a very legal fashion. I think it does not necessarily make it as clear as you perhaps explained it now.

**Mr Winninger:** I want to assure you that we are looking at the issue that has been raised by Mr Poirier earlier of families that have relatives outside the province and how relatives outside the province might be allowed to become guardians, looking at possible models or mechanisms to make that work, particularly in the eastern townships where families tend to be distributed across the border.

1540

**Mr Poirier:** Ontario's eastern townships.

**Mr Winninger:** Ontario's eastern townships.

**Ms Diakun-Thibault:** That is an interesting title.

**Mr Villeneuve:** It is a new terminology.

**Mr Poirier:** The geographer in me is being tortured now.

**The Chair:** Order, please.

Ms Diakun-Thibault, on behalf of this committee I would like to thank you for taking the time out this afternoon to give us your presentation.

**Ms Diakun-Thibault:** Thank you very much. In retrospect, I guess I should be happy I did not become a moot point. I would like to say that personally I certainly welcomed hearing there was a motion, albeit defeated.

**The Chair:** We are waiting for our next presenter. He will be back shortly. Mr Poirier, did you have something you wanted to raise?

**Mr Poirier:** Yes. I received on March 23 a letter from somebody who came forward some time ago, as you may recall, Dr John Cleghorn, from the Clarke Institute of Psychiatry. After hearing his presentation, I had brought up to him the fact, after hearing a lot of people, that a lot of people had some strong objections to the way they felt they had been treated either at the Clarke or elsewhere. I got the following letter from Dr Cleghorn. I think there was a copy sent to the parliamentary assistant, the member for York East, and also to Mr Sterling from the Tory caucus. For the record, if I may, I would like to read it and then we can discuss this afterwards.

**The Chair:** Sure.

**Mr Poirier:** It is dated March 17:

"Dear Mr Poirier

"Following my testimony to the standing committee on the administration of justice on Tuesday, March 10, 1992, I remained puzzled by the complaints made by patients that you mentioned that were so disturbing. Puzzled because these people do not seem to behave like other aggrieved persons.

"Psychiatrists in psychiatric institutions are not flooded with allegations of wrongdoing. So far as I know, there is no great increase in complaints about psychiatrists lodged with the College of Physicians and Surgeons. The patients do not make direct complaints to us in our clinical settings, although there is in fact plenty of opportunity for them to criticize the way in which they are being treated, and to enter into dialogue and to negotiate alterations in the way in which they are treated. Undoubtedly, some abuse occurs but I believe it is occasional and sporadic.

"A small number of patients, unfortunately, become delusional about their doctors and other caretakers and develop persecutory ideas about what has happened to them that are in fact unrealistic. Some of these people are coherent and well-organized so that it would be very difficult to distinguish between them and those with well-grounded complaints.

"May I suggest that hearings into these allegations be held and that the professionals named by patients who feel

they have been wronged be requested to come to the hearings to shed light on what has actually transpired. I would be pleased to use my influence with my colleagues to ensure that they cooperate.

"Please let me know if I can do anything to help resolve these issues.

"I copy this letter to Mr Malkowski and Mr Sterling since they are also intensely interested in this problem and you certainly have my permission to share this letter with other members of the standing committee on administration of justice.

"Yours sincerely, John M. Cleghorn, MD, Professor of psychiatry; Head, schizophrenia research program, Clarke Institute."

You will recall, and I think all of us were kind of shocked, what some people said when they came forward, especially those who were active members of survivors' groups, and the presentation of Dr Cleghorn—

[Interruption]

**The Chair:** Order. This is an extension of the House. Could you please leave the room. Thank you. Just a reminder, this is an extension of the House and no comments will be tolerated from the people visiting the committee.

**Mr Poirier:** Obviously with such a diversity of opinions, strong opinions one way or the other, as you witnessed, it is very disconcerting. The allegations of some of these members of the survivors' groups were very disturbing. Then I see Dr Cleghorn's position, and I am sure other psychiatrists feel this way. This is very much a black-and-white situation here. I am very disturbed. I am glad Dr Cleghorn wrote this and is offering to help us look into this.

I do not know how you feel, and I do not want to predispose myself one way or the other on whichever side, but from the allegations we heard from people who are members of psychiatric survivor groups, whoever is sponsoring these groups—and we know some of their members and I do not feel like mentioning some groups right now—when you hear this side of the story, I think it is a matter for us to look into. If we believe in advocacy, in the principle of—something is wrong somewhere in communications.

When I first read this letter, I said to myself, is there any way the members of this committee can help improve and create a forum for people to come forward and for the psychiatrists and members of the profession like Dr Cleghorn and others, whether we are talking about the Clarke Institute or wherever else, to help bring them closer? From my presence here and from what is claimed in here and from what the survivors have claimed, there seems to be a hell of a problem with dialogue between givers of health services and those on the receiving end.

I would like to put a motion forward that this committee could use at least a 12-hour period to look into ways to bring forward the two sides in this debate and see how we, as members of this House, together can look at how we can resolve what I feel is a very serious situation and a very disturbing situation. I do not know if my colleagues want to respond, but I would invite their response to this formal motion.

**The Chair:** Mr Poirier moves that the standing committee on administration of justice accept the suggestion brought forward by Dr John Cleghorn of the Clarke Institute that hearings into the allegations of abuse of patients by some psychiatrists be held so that people on both sides of the story could come forward and testify in front of this committee.

**Mr Morrow:** Mr Poirier, I will be supporting your motion. I do believe you are looking for a section 123, a 12-hour debate.

**Mr Poirier:** Yes.

**Mr Morrow:** I will be supporting that. Not only will I be supporting that, I will be urging my fellow caucus members to support that. I think we have heard issues on both sides of this. There obviously is a problem here. If there is anything we can do as legislators to try and resolve this, I think it is incumbent upon us to do that.

**The Chair:** Just a reminder to the committee that we could do it under section 106. It does not have to go under section 123.

**Mr Winninger:** I certainly support what my colleague Mr Morrow had to say, with this caveat: I am a little concerned with the way in which certain patients have been hindered, if I might use that word, from coming forward to testify before this committee. It would concern me if the patients who were willing to speak well of the facilities in which they found themselves were allowed to come while others, due to medical opinion, were suddenly denied that privilege. That is one concern. I think we have to be consistent in our approach to the manner in which we elicit evidence from patients.

Also important is that I think we have to come to terms with the question of costs again, because if there are executive directors of facilities or medical directors who decline to bring people here at their own expense, then we have to be prepared, if we are going to have a meaningful discussion as to the issues raised in Dr Cleghorn's letter, to pay the cost to bring people here with or without their security people and their attendants.

**Mr Malkowski:** Could we perhaps recess for 10 minutes to discuss that and consider the motion?

**The Chair:** There is a call for a 10-minute recess. We will resume at 3:59.

The committee recessed at 1550.

1603

**The Chair:** I call the committee back to order.

**Mr Poirier:** After a very fruitful 10-minute break, I think there was unanimous consent given that I could bring back my resolution and add the following to it, that I want to make sure that the motion that I made did specifically state that it was part of the ongoing investigation or the work of this committee, the justice committee, to make sure that if we proceed with this mandate, as is my request in the motion, it be part of the overall mandate to study the bills we have in front of us, because the content of this letter is emanating out of presentations that were made by people on both sides of the fence in this issue. I do not have the exact words, but I am sure the clerk will add the

necessary wording to make sure this resolution is in order for us to be able to consider it.

Furthermore, I would like to state that I think we should wait a while before voting on this motion. We discussed during the break and I think we will have to look into legal counsel's opinion pertaining to the nature of how we can look into these allegations and how we can proceed with the type of request Dr Cleghorn has suggested, to look into these allegations that some of the patients, or former patients, have brought forward. With the committee's indulgence, I ask for its support to accept the principle of this motion. We can consult with legal counsel. After we have received advice from legal counsel as to how we can go about doing this, then we can vote at a particular time on this to find out how and where we proceed with this further work of our own committee.

**Mrs Sullivan:** I think the content and intent of the motion that Mr Poirier has put forward are of some importance in terms of dealing with the credibility of some testimony before the committee and, as well, the determination of the extent of need evidenced to the committee in relation to the bills put forward.

The concerns I have and the reasons I will be supporting the amendments to Mr Poirier's motion relate to the fact that we know there is an OPP investigation now occurring into similar charges of abuse at Oak Ridge. That investigation could or could not, may or may not, lead to criminal charges. There is a question as to whether the kind of setting of the record on the table before this committee may indeed be beyond the mandate. This could be a different kind of investigation beyond the mandate of this committee.

I am concerned as well about the nature of the defence, I suppose, that would be necessary for the health care professionals to put before the committee, including what may be access to clinical or medical records of people who indicated a particular concern. It would probably, in that instance, behoove the committee to ensure that there was appropriate consent for the release of those records and some question relating to the confidentiality provisions, whether under the Public Hospitals Act or the Mental Health Act, and the concurrence of the patients themselves.

For those reasons, I think the rational approach is indeed to have legal counsel in relation to this motion. Clearly the issues that are of concern are broader than the specifics included in the motion. I think that the committee should approach the content of the motion and the issues associated with it with full advice of counsel and that the motion should be put over until the next session of the committee.

**Mr J. Wilson:** I am supportive of the motion, as I understand it, but I would not want to see this get too complicated, as I think Mrs Sullivan is suggesting. My understanding, and please correct me if I am wrong, Mr Chairman, is that there were allegations made and doctors named and the doctors themselves, through the chief medical officer of the Clarke Institute, would like the opportunity to explain their side of the story. I do not think it gets much more complicated than that. The concern I would

have in their explaining their side of the story is shared with Mrs Sullivan, and that is confidentiality. That may be overcome by doing a one-day in camera session or whatever advice the Chair and counsel may have on that.

Finally, I have no qualms whatsoever with deferring the vote on this motion until the next sitting of the committee, but I do not know when the next sitting of the committee is, and since our subcommittee meetings have been cancelled, we do not know when amendments are coming, we do not know when clause-by-clause is supposed to be. The phone calls will start coming into our offices later this week asking us: "Are we left in limbo? When are we supposed to meet again?" All we know is that the House is coming back on April 6. I think it is imperative upon the government right now to clear up the confusion over when the committee will sit again in the process.

1610

**Mr Wessinger:** I would just like to concur in the recommendation that the matter be deferred, because I do think we need the advice of legal counsel. I have several concerns about whether some of the suggestions within the motion are appropriate to be dealt with. I think it is important that we have the advice as to all the ramifications.

**Mr Morrow:** Because I spoke on Mr Poirier's motion in the first place, Mr Poirier, I will be supporting what is I suppose an amendment to your first motion and I will also be supporting deferring to legal counsel.

**The Chair:** Do we have unanimous consent to defer this to legal counsel for advice?

Agreed to.

**The Chair:** Anything further before we proceed to our next witness?

**Mrs Sullivan:** Mr Chairman, I would at some point appreciate a clarification of the next stage in the process in consideration of these bills. My understanding is that the steering committee has left the committee in a position where the next step now is to proceed to clause-by-clause. Even that would give an indication that there would be no opportunity for amendment in a consolidated fashion, and perhaps after the next witness, I would like to have a fuller discussion of this issue.

**The Chair:** Thank you, Mrs Sullivan. It sounds appropriate.

SUE GOODWIN

**The Chair:** Good afternoon. Our next witness is Sue Goodwin. Just a reminder that you will be allowed a half-hour for your presentation. The committee would appreciate it if you keep your remarks to about 15 minutes to allow time for questions and comments from each of the caucuses. As soon as you are comfortable, could you please identify yourself for the record and then proceed.

**Ms Goodwin:** Good afternoon. My name is Sue Goodwin. I greatly appreciate this opportunity to speak to you about legislation I cannot wait to see proclaimed in this province. Again, my name is Sue Goodwin. I am a 29-year-old psychiatric survivor. I consider myself qualified

to speak to you as a consumer of mental health services in Toronto for the last decade.

And I am a survivor. I have survived three psychiatric hospitalizations, inappropriate and toxic drug therapy, mislabelling and other intrusive attempts to remove permanently, I guess, my sense of humour. But I am very glad I survived to see legislation like Bill 74 being proposed. I am only going to speak to this bill today and not the others, because I agree with many of the other deputations you have heard, and that is that the consent to treatment and substitute decisions bills should be delayed a couple of years after Bill 74 is implemented and after it goes into effect.

Like other survivors in this province, I owe a heartfelt thank you to the 35 progressive organizations of the Ontario Advocacy Coalition which lobbied and worked so hard for the creation of a publicly funded advocacy system to defend the rights of vulnerable people. Also, my gratitude goes out to the forward-thinking legislators of the current NDP administration, who have recognized that it is about time to end the abuses in our psychiatric treatment system and finally give us, the vulnerable psychiatric patients and survivors, some basic human rights. I applaud the creation of an Advocacy Commission comprised of people like me, people other patients can talk to without being intimidated or coerced, people who have been there.

On this point, I would strongly recommend one change to clause 36(b) of Bill 74. I would ask you to amend it to read, "establishing minimum qualifications and performance standards for advocates," rather than "educational standards," as it now reads. My rationale is this: Since when does formal education become excellent preparation for effective advocacy in a totally foreign environment, like a psychiatric hospital or a boarding home? I think my own expertise and that of other survivors stems directly from my experiences as a vulnerable person in these chambers of horror, rather than from my educational degrees.

Simply put, I am here to urge all of you to speed the proclamation of Bill 74 as much as possible. Like others who have spoken to you, I would ask that Bill 74 be implemented two years prior to the other bills being enacted. I agree with many of the changes to Bill 74 suggested by the Ontario Advocacy Coalition, but I would rather see this important legislation passed in this current session of the House than see it perfected by much redrafting and lost to eternity.

I am also here to counter some of the previous testimony I have read in preliminary transcripts of this committee's February hearings and earlier this month, testimony from people like Dr Cleghorn of the Clarke, Dr Fleming from Penetanguishene, testimony from those I call "the forces of darkness," these psychiatrists, other medical and family-type powers that be who would love to see this proposed legislation go in the garbage so there would not be these irritating challenges to their powers to decide who gets what treatment, when, where and how: irritants like basic human rights for us; an irritant like an advocate helping me or any other vulnerable person to determine and enforce my right to refuse to be forced to undergo brain-disabling shock treatments or my right to

refuse new and untested drugs that give me an equivalent to a chemical lobotomy; my right to be aware of and seek less intrusive psychiatric help in the community instead of being locked up in a cold mental hospital, pumped full of chemicals, talking to a psychiatrist for about four minutes a week, and other blows to my life and my self-esteem and my livelihood.

While I have a great deal to praise about Bill 74, I do have a few strong suggestions. Clause 7(1)(f) of this legislation directs the commission to provide advocacy services that take into account religion, culture and traditions of the vulnerable person. This committee should also ask that an addendum to this section be added about gender and sexual preference. Statistics show us that the majority of psychiatric patients are women. We need special protection in these institutions and there should be an emphasis on women as well as minority advocates.

One of the things I would hope this committee would be able to amend in the legislation is the enforcement that is set out in various sections. The enforcement should be done conscientiously. A \$5,000 fine for whomever is contravening the law is great, but only if the act is enforced, and I would like to see it enforced.

Thank you again for the opportunity to speak to you and I would be happy to answer any questions you may have.

**Mr Mancini:** Thank you for your brief, Susan. You have asked the committee to proceed speedily with Bill 74 but to delay the other bills. Is there any reason why you want the other bills delayed?

**Ms Goodwin:** The Advocacy Act is, from my point of view and from the other survivors I have spoken to—I have spoken to a great many survivors. I am a member of Toronto Psychiatric Survivors. In fact, I work for them. I am also a member of the Ontario Psychiatric Survivors' Alliance. I am a member of the Supportive Housing Coalition of Metropolitan Toronto and a lot of organizations where I have met hundreds of other people like me. We all feel Bill 74 is very important to us. It is a wonderful piece of legislation, but for the others, Bill 108 and Bill 109, the Consent to Treatment Act and the Substitute Decisions Act, we would like to see Bill 74 put in place first, prior to those other two pieces of legislation, or even Bill 110, just to see how the advocacy part of it gets functioning well first before the other bills are brought in.

**Mrs Sullivan:** Ms Goodwin, I am interested in your suggestion that Bill 74 proceed before 108 and 109. We had assurances from the parliamentary assistant yesterday that the three bills would proceed at the same time and as a package, as they were introduced. So it is clear the government has made up its mind on that issue.

One of the suggestions I was also going to make to you was that if the Substitute Decisions Act was delayed, the advocate would then be left in a position of in fact becoming a decision-maker, which has been put to us as not the role of an advocate. Would you like to comment on that?

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**Ms Goodwin:** I have to agree with you there. You are absolutely right. The advocate cannot make a decision for a person. It is their individual right to do it. Then I stand

corrected. I guess the other bill, the Substitute Decisions Act, would have to be put in place at the same time.

**Mrs Sullivan:** Could you define, because it is not defined in Bill 74, what you see as the role of the advocate, the training required, the scope of practice and the disciplinary or accountability requirements for an advocate?

**Ms Goodwin:** I would be defining it solely from my position as having been a vulnerable person at various times over the last decade. I could see an advocate acting on my or any other person's behalf, whoever is in the vulnerable position, in either an institution, a boarding home, a group home or any other sort of institution or treatment place. In the training they would have to have, it would be very nice to see a training package that is developed not necessarily strictly by academics or bureaucrats but people out in the community, such as a few of the groups I have mentioned to you I have been associated with, with their knowledge, because we have the knowledge. We have been there, so we should definitely be in on helping to develop the training package. I think that is in Bill 74, I think section 7, that the commission does not have to do everything directly but can use community groups to do the training through and that sort of thing.

**Mrs Sullivan:** There has been some concern raised before the committee that the advocate should have knowledge of the disease, the illness, the particular disability that has led to the person's incapacity. Do you concur with that?

**Ms Goodwin:** I suppose yes, I concur that the advocate should be trained in what traditional medical science believes these illnesses are. They should also be trained in the alternative points of view that in fact these are not chemical illnesses, they are society-imposed and behaviour-imposed illnesses.

For instance, I have been labelled as a person with a personality disorder, a hypomanic, a seasonally adjusted depressant. What else have I been called? I think that is about it, thank God. Anyway, I do not consider myself any of those things and I have not exhibited lasting characteristics of someone with that supposed mental illness or mental disability or whatever other people want to call it.

While yes, it would be valuable for an advocate to know what are the traditional symptoms and blah-blah-blah of a schizophrenic or a hypomanic or whatever the heck you want to call us, he or she should also be aware that in a great deal of cases these are people who have been mislabelled by the psychiatric institution they are in.

I know you have had other people come before you, Hugh Tapping and quite a few other speakers, who have been labelled at various times as various things, and lo and behold, they are just normal people and they are just fine right now.

**Mrs Sullivan:** I suppose the question really related to not only those illnesses or impairments that are considered psychiatric but, by example, those which may be degenerative, such as Alzheimer's. To know the manifestations of Alzheimer's, it has been put to us, is important in knowing how, when and in what manner to provide advocacy services.

**Ms Goodwin:** Yes, I can see your point there. I agree it would be invaluable for the advocates to know those things. I do not think they have to be taught in a medical teaching hospital. There are lots of community groups, such as the Alzheimer's association, where they know as much, if not more, than any of the doctors do about those sorts of things. I do not think you have to turn people out of university with a degree and then they will be trained in recognizing all these medical things and they will be ideal advocates. They will not be. It takes some other kind of training as well.

**The Chair:** Ms Goodwin, on behalf of the committee, I would like to thank you for taking the time out today and coming and giving us your presentation. Resuming where we left off, Mrs Sullivan.

**Mrs Sullivan:** I suppose that is right. I want to make note of the fact that I was surprised the government members did not make questions or comments in relation to the recommendation that one bill be proceeded with, although I indicated to the witness that the government had indicated the bills would proceed and be dealt with at the same time. That clearly is an issue that has been expressed by many groups, a matter of concern, and we need to know how we are going to deal with these bills.

Frankly, I think without any indication of when amendments are going to be put forward by the government, what period of time there will be for consideration of those amendments, when clause-by-clause will proceed—as I indicated, my understanding is that the committee so far has determined that at the conclusion of public hearings, which is now, clause-by-clause will proceed immediately.

**Mr J. Wilson:** Are we going to get an answer to this stuff or do you want us just to filibuster and debate this all night? Where are we going from here? It has been weeks to figure this out. Do you have any rough idea of what the time frame is, perhaps?

**Mr Mancini:** Do you know what you are doing? That is the question.

**Mr Morrow:** That is fair.

**Mr Mancini:** Then why do you not tell us?

**Mr Morrow:** Can I let Mr Malkowski answer this, please?

**Mr Malkowski:** As we have mentioned this afternoon, first of all, we need more time to consider what we have heard and to get the information back to you later.

**Mrs Sullivan:** Mr Chairman, if I may, that is not a satisfactory response. There has been a determination by the subcommittee that the committee will proceed after public hearings into clause-by-clause, and we now hear, "We'll get back to you." That is absolutely irresponsible. Earlier today, a motion that put forward a reasonable, legitimate process for dealing with these bills was defeated by the government majority. What is the government's intention? Could we hear it perhaps from the Vice-Chair of the committee or from any of the parliamentary assistants? This is ludicrous.

I would be delighted to go back and reach every person who appeared before this committee by fax this afternoon

with the information that the government members have advised us they will get back to us when they have decided, when they have their house in order, what the process is going to be. Clearly, this is a government in disarray.

**The Chair:** One piece of clarification is that the natural process is to automatically go to clause-by-clause now.  
1630

**Mr Wessenger:** I guess that was my question. I wanted to know what the process would be. There has been no subcommittee decision on clause-by-clause, so I had assumed, maybe incorrectly, that if there was no subcommittee decision then it would not proceed until there was a subcommittee decision. Am I wrong in that regard?

**The Chair:** You are wrong. The natural process is that we will proceed to clause-by-clause, absent any motion to the contrary.

**Mr J. Wilson:** When is that going to be?

**The Chair:** That will happen at the next meeting of the committee, and the committee will meet at the call of the Clerk of the House.

**Mr Wessenger:** The next meeting of the subcommittee then, is that correct?

**The Chair:** No. At the next meeting of the whole committee, we will proceed to clause-by-clause.

**Mr J. Wilson:** Are you guys going to show up at the next meeting of the subcommittee, or do we have to—

**The Chair:** Would you like the clerk to explain this?

**Mr Wessenger:** I think it might be helpful to all members of the committee, yes.

**Clerk of the Committee:** Essentially, because there will be a throne speech, the committees get reconstituted. Once the committees get reconstituted, there is no Chair, no Vice-Chair, in essence no committee. So the first meeting of each session is always called by the Clerk, at which point we elect a Chair and a Vice-Chair. At that point, absent any motion to the contrary, we would continue with the business of the committee.

**Mr Wessenger:** An appropriate motion could be made at that meeting, then, too.

**Clerk of the Committee:** Motions can always be made.

**Mr Winninger:** I was just going to suggest that indeed it would be premature to try to bind the hands of the new committee members in the new Legislature. Consequently, I do not think an allegation that this government is in disarray is well founded. We are heading into a new session, a new constitution of a committee. Let that committee deal with it as and when it sees fit.

**Mr J. Wilson:** There are a couple of problems here. We have a motion from Mr Poirier that, as a continuation of these committee hearings, we deal with the concern of Dr Cleghorn, so that is up in the air. Second, during the Regulated Health Professions Act hearings in the standing committee on social development, a representative from each caucus did show up at the subcommittee meetings. In the last two subcommittee meetings of this committee,

there has been a no-show by the government, so we were unable to proceed with the subcommittee meetings. Surely to goodness you know when you want the committee to meet again so we can deal with Cleghorn and start to prepare for clause-by-clause. You cannot just leave us in limbo. We had much better cooperation from you, Mr Wessenger, during the RHPA hearings. Why are we not seeing that same level of cooperation during these hearings? I do not understand it.

**The Chair:** Thank you. Mrs Sullivan.

**Mr J. Wilson:** That is actually a question, Mr Chair.

**Mr Wessenger:** I can only assure you, you will have cooperation.

**Mr Mancini:** To the four parliamentary assistants who are here, I assume you regularly meet with your ministers.

**The Chair:** Order, please. Mrs Sullivan has the floor.

**Mr Mancini:** I am sorry, Mrs Sullivan.

**Mrs Sullivan:** I notice Mr Winninger spoke about binding the hands of the new committee and therefore refusing to provide any indication of when the government would have amendments, how it would be proceeding with those amendments to ensure they are put forward in an understandable way and appropriate comment and analysis could be done. I would like to remind you that documentation is being made public about this government's intention to proceed with these bills in the Legislature in this current spring session. How can Mr Winninger say he does not want to bind the hands of the committee? How can Mr Malkowski say, "We'll get back to you"? This is absolutely irresponsible. I have never seen anything like this at the House.

**Mr Poirier:** Those are exactly the words I wanted to use. I have been here for seven and a half years and I never thought I would see something like this. There is something very wrong within your government, and I say this in a very friendly term.

**Mrs Sullivan:** It starts at the top.

**Mr Poirier:** It starts somewhere, but we are seeing the result right here today. I have seen seven and a half years' worth and I never thought I would see this. I cannot believe that you believe this is such an important piece of legislation, all of these bills, and these are the answers you are giving us today. It is thoroughly unbelievable, and if you had been here for seven years you would understand where I am coming from. I do not understand that.

You do not seem to have anybody to advise you on what the process is. This is being done usually on a continuous basis. It is not done in a vacuum. It is not a summer project. It is not a four-month project that you have to reply to and start at zero again every four months, guys. Something is wrong with how you are doing this and a lot of the people who put a lot of faith in this process must be wondering right now. As we say in a highly technical term, what the hell are you doing? Where are you going? I have never seen this and I really cannot believe what I am hearing.

I am extremely concerned and worried because we have invested a heck of a lot of time. We suspect you have a very long list of amendments. You can know right away

that at least we, and I think the Tories, have a very long list of amendments, because of what the people said when they came in front of us. And you just say, "Well, we'll send you a postcard from somewhere and we'll tell you when we resume again." It is not a question of binding the hands of those who follow; it is to continue a very serious process where a lot of public servants, counsel, volunteers, groups, individuals inside and outside this place, have been working years and years to get to here.

When you stop and think of that—and I listened to your answers—wow. I do not know how to react. I am trying to be as polite as I can but I am having a hell of a hard time. I just cannot believe this. Go back to your caucus, go back to your advisers and tell them to get off their buns and get going. Say something, do something; just do not refer us to legal counsel and advisers and "We'll get back to you," with all due respect. You have been there a year and a half now. You will have to get into the driver's seat. Please.

**Mr Malkowski:** It is still early to discuss. I think what we want is more time to be able to discuss what we have heard, and I would like to propose a motion for adjournment today, please.

**The Chair:** We have a motion to adjourn. All those in favour?

**Mr Mancini:** Let's have a recorded vote, because the committee is being stymied here. Is that the answer to the committee members when we want to have a discussion as to where the committee is going, that some member of the government makes a motion to adjourn? That is the government's answer?

**The Chair:** The motion to adjourn is not debatable. A recorded vote on the motion to adjourn.

**Mr Morrow:** You have taken the vote already. How can you ask for a recorded vote now?

**Mr Mancini:** I want a recorded vote, Mr Chairman.

**The Chair:** Recorded vote. All those in favour of the motion to adjourn?

**Clerk of the Committee:** Mrs Carter, Mr Wessinger, Mr Winninger, Mr Morrow.

**The Chair:** All those opposed?

Interjection.

**Clerk of the Committee:** I did not see Mr Malkowski's hand. Mr Mancini, Mr Poirier, Mrs Sullivan, Mr Wilson.

**Mr J. Wilson:** For the record, Mr Malkowski did have his hand up, Madam Clerk, for the affirmative. She missed him in the recorded vote.

**The Chair:** The committee stands adjourned at the call of the Clerk.

I have one announcement to make before everybody walks out.

**Mr Mancini:** We are adjourned.

**The Chair:** I know, but this is just for your information.

**Mr Sterling:** We are adjourned. Speak to the government members.

**The Chair:** I will say it anyway. The summary will be out on next Friday. The cutoff date is this Friday for briefs to be included. The briefs will be distributed if they come in afterwards.

The committee adjourned at 1638.

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 Sorbara, Gregory S. (York Centre L)  
 Sterling, Norman W. (Carleton PC)  
 Wessenger, Paul (Simcoe Centre ND)  
 Wilson, Jim (Simcoe West/-Ouest PC)  
 Winninger, David (London South/-Sud ND)

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Ferguson, Will, (Kitchener ND) for Mr Fletcher  
 Johnson, Paul R. (Prince Edward-Lennox-South Hastings/Prince Edward-Lennox-Hastings-Sud ND) for Mr Fletcher  
 Mancini, Remo (Essex South/-Sud L) for Mr Sorbara  
 Sullivan, Barbara (Halton Centre L) for Mr Chiarelli

### Also taking part / Autres participants et participantes:

Spinks, Trudy, legal counsel, Ministry of Citizenship  
 Ward, Brad (Brantford ND)  
 Villeneuve, Noble (S-D-G & East Grenville/S-D-G & Grenville-Est PC)

**Clerk / Greffière:** Freedman, Lisa

**Clerk pro tem / Greffier par intérim:** Brown, Harold

**Staff / Personnel:** Swift, Susan, research officer, Legislative Research Service

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